

Lessons From the Front Lines



Trans Health and Rights

**In addition to amfAR,
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*Cover photos (clockwise from top): Grantee partner colleagues from **Gender Dynamix** in Cape Town, South Africa; The Thai Transgender Alliance (**ThaiTGA**) in Bangkok, Thailand; and Centro de Orientación e Investigación Integral (**COIN**) in Santo Domingo, Dominican Republic.*

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Introduction

All around the world there are people who self-identify with a different gender than the one assigned to them at birth. Very often, these people also challenge normative assumptions about gender expression and contradict cultural expectations about bodies, behaviors, and appearances. A variety of names have been used to identify these people in different countries and cultures, including those of two spirits, transmen and transwomen, travestis, fa'afafines, transsexuals, and hijras. In the context of the global HIV response, they are internationally recognized as transgender or trans people.

Trans people face very similar challenges across the globe. These challenges include early rejection and exclusion from family, society, and community life. Many trans people therefore lack access to education, and a high number of trans adolescents are homeless. Many are forced to leave their families, communities, towns, and countries to survive, and many become legal or illegal sex workers. Trans people in general, and trans sex workers in particular, are constantly exposed to discrimination, harassment, persecution, arbitrary detention and incarceration, torture, and murder—and these human rights violations against them are usually not investigated.

In most countries, trans individuals cannot get legal recognition of their gender identities. When legal recognition is available, it usually requires psychiatric diagnosis of gender dysphoria or a similar condition, sterilization, surgeries and hormonal treatments that may not be wanted, forced divorce for individuals who are currently married, and other requirements that are blatantly incompatible with human rights standards. Many of the same discriminatory requirements often apply to those who want to access gender affirming procedures, such as surgeries and hormone treatment. As a consequence, many trans people around the world modify their bodies through dangerous methods, such as self-injecting industrial silicone or oil, or accessing surgeries or hormones through illegal markets.

These social and institutional barriers make trans people extraordinarily vulnerable to depression, substance abuse, suicide, and HIV infection. Their HIV risk is heightened due

to the pervasive combination of stigma and discrimination, lack of access to healthcare, stable housing, and employment, substance abuse, and being subjected to sexual violence. These same factors also prevent trans individuals, and trans sex workers in particular, from accessing HIV information, prevention, and treatment. In many countries, little data exists on the trans population and HIV, but when it is available, the reported prevalence of HIV among the trans community is often higher than among gay men and other men who have sex with men (MSM) and far higher than among the general population.

However, as this report will demonstrate, trans individuals worldwide have responded to the epidemic with a process of intense political organizing on the local, national, regional, and international level. Trans community organizing has been the key to differentiating between the epidemiological, prevention, treatment, and political issues faced by MSM from those faced by trans individuals and to then developing a response designed to specifically target trans individuals' HIV needs.

This report profiles ten organizations committed to improving trans people's living conditions by challenging social and institutional constraints, supporting community empowerment and leadership, and developing a response to HIV designed for and by trans individuals. Most of the organizations are led by trans people themselves. All ten are current or former grantee partners of amfAR's GMT Initiative and are located in Africa, the Asia-Pacific, the Caribbean, Eastern Europe and Central Asia, or Latin America.

Members of each organization were interviewed by Mauro Cabral, the co-director of Global Advocacy for Transgender Equality (GATE). They offered accounts of their project goals during the period they were funded by the GMT Initiative, the challenges they faced in achieving those goals, how the challenges were confronted, solved, or incorporated into new strategies, results from amfAR-funded studies they performed when available, and the lessons they learned.

Organization Profiles

Red Nacional de Mujeres Travestis, Transexuales y Transgéneros de Bolivia (RED TREBOL)

Cochabamba, Bolivia

RED TREBOL is a network of trans people that consists of over 1,000 participants and six facilitators who work in six areas of Bolivia (Beni, La Paz, Cochabamba, Potosí, Oruro, and Santa Cruz). The network was created in 2008 during the first national meeting of trans advocates held in Santa Cruz de la Sierra. RED TREBOL performs strong advocacy work for the legal recognition of gender identity and for trans access to education, health, and employment. It also provides legal advice and HIV information, prevention materials, and counseling.



Rayza Torriani, director of RED TREBOL, being interviewed about a proposed Gender Identity Bill.

Year 1:

RED TREBOL first received amfAR support to organize workshops to train and empower trans leaders and encourage their participation in decision-making processes. They also organized workshops on gender identity for media, grassroots organizations, and educational institutions, and trainings on health issues for medical professionals. As part of the project, the organization also conducted strong advocacy work with government officials and created a sustained media visibility through posters, videos, and radio ads.

Results:

With the support from amfAR (and other agencies, including UNDP, UNAIDS, and UNFPA) RED TREBOL worked with a National Working Group on HIV and Sexual Minorities to organize the first national meeting on Human Rights and Gender Identity. It took place in October 2013 and was attended by over 60 representatives, including senators, both national and local

government authorities, foreign officials, and advocates from other countries. “It was a milestone for the trans population in the region,” says RED TREBOL’s director, Rayza Torriani.

Year 2:

Meanwhile, the female trans population’s right to health in Bolivia remained a pressing problem, and trans women continued to experience abuse from health providers. The hostility of the medical system not only prevented many trans people from accessing HIV treatments, but also caused them to self-administer industrial silicone to change their body to express their gender—a practice that can be deadly.

As a result, RED TREBOL recognized the need to establish its own space to provide healthcare. “It is not only a space for physical health, but also for mental health, and for the sisters to find a place that includes them, because you cannot fight against HIV if you are made to believe that you are worthless,” says Rayza.

Using amfAR’s support, RED TREBOL opened a clinic this year at its headquarters in Cochabamba that provides HIV and other medical care and specialized information on hormone treatments, and also addresses other health issues, including complications with silicone implants and alcoholism.

Results:

The clinic operates three days a week and staffs a nurse who provides medical services and psychological and emotional support. Unlike at other health centers, identity and gender expression is respected and the patients receive warmhearted services. RED TREBOL’s clinic works in coordination with other government-run health centers. The project is not intended to compete with the state, but to help expand trans individuals’ access to healthcare, when state facilities do not provide transphobia free services. The office has the endorsement of the National Health Program.

The project also includes continued training for health professionals; however, as Rayza warns, “It is necessary that the state takes responsibility and intervenes in the training of health professionals, because doctors trained by us are then replaced by others, and who will ensure their training when we cannot do it?” Meanwhile, RED TREBOL continues its work to promote sustained trans leadership. “For us, it is fundamental to believe that this can be done and that we can do it, so we lose the fear,” says Rayza.

Lessons:

- Training health personnel is not enough. Continuous engagement is essential to provide trans-friendly health services.
- Activists cannot and must not replace the government’s responsibilities. They should lobby for their government to meet its responsibilities in servicing all people, including the trans community.
- Progress begins and is sustained by strengthening trans leaders.

Chengdu Tongle

Chengdu, China

Chengdu Tongle started in 2002 as a gay organization and has grown to focus on providing services for HIV prevention, testing, and counseling; organizing cultural activities; and promoting advocacy on LGBT issues in China. Chengdu Tongle has extensive experience in mobilizing the LGBT community through outreach activities, trainings, and peer support. It's also an organization with a solid background in advocating against institutional homophobia and transphobia in healthcare settings in the region.

Years of working with LGBT in the field demonstrated to Chengdu Tongle that the trans community's situation was different than that of gay men and other MSM, due to challenges associated with gender identity and expression, sex work, stigma, discrimination, and exclusion, and that they needed to develop programs and strategies specific to the trans community. Chengdu Tongle decided that the only way to seriously address the challenges faced by trans people in Chengdu was to involve the trans community as the primary participants and leaders in the process. In 2010, Chengdu Tongle received an award from



Members of Chengdu Tongle at their offices

amfAR for a groundbreaking project focused on the Chengdu trans population. "They deserved to be considered as what they are, trans people and not gay men," said Yu Fei, chief executive officer of Chengdu Tongle.

Chengdu Tongle developed a project that articulated three main strategies: performing participatory research, improving organizational capacity, and advocating the government to address trans issues. Developing this project required learning how to work with the trans community to distinguish and appreciate its diversity, the particularity of its needs, and its own road to empowerment.

Results:

Chengdu Tongle was able to recruit participants because of its long-standing relationship with the local trans community and its close proximity to bars where trans people often meet and work. Chengdu Tongle involved more than 60 trans participants in designing a participatory assessment of their needs, expectations, and resources. This included different sub groups, such as cross dressers and trans sex workers.

This assessment process combined face-to-face interviews with focus group discussions to provide an accurate overview of the challenges and opportunities faced by trans people. The experience produced much-needed knowledge about the community, including their needs for respect and recognition and for doctors trained to deal with their specific issues. It also empowered them, opening the way to the next step in the process—the creation of the first trans organization in Chengdu.

Chengdu Tongle had envisioned establishing a specific organization that addresses trans issues at the beginning of the project, and the participatory research created the community involvement needed for the organization to succeed. The name of the organization is New Beauty, and its mission, goals, and work plan were developed by the involved trans activists, with Chengdu Tongle contributing as a facilitator. "This is their organization, and not ours," said Yu Fei. However, New Beauty has not been able to legally register as a formal and independent organization, and, therefore, Chengdu Tongle has continued to operate as a host, and the trans people involved in New Beauty as volunteers. For Chengdu Tongle, this is a clear example of the discrimination against trans people in China.

The project faced a similar challenge in terms of advocacy. Even with the well-researched knowledge and suggestions about the specific healthcare needs of trans people produced by the project, the organization is still struggling with the government's reluctance to incorporate that knowledge into official strategies for HIV prevention.

Lessons:

- Community mobilization requires building knowledge through participatory research processes that involve the community.
- Separate strategies need to be implemented for MSM and trans people, and the diversity among trans people needs to be recognized.
- Political solidarity within the entire LGBT community is necessary to overcome expected and unexpected challenges.
- Despite the government's unwillingness to accept results and implement programs, Chengdu Tongle's work is still vital to providing these important services to trans people.

Comunidad de Trans y Travestis Trabajadoras Sexuales Dominicana (COTRAVETD)

Santo Domingo, Dominican Republic

COTRAVETD promotes the human rights of the female trans population in the Dominican Republic. Its activities are focused on providing HIV prevention, support, and treatment access and community and societal awareness about the stigma, discrimination, and violence trans people, people living with HIV, sex workers, and Haitian immigrants to the Dominican Republic often face.

COTRAVETD also performs advocacy work for the recognition of the right to gender identity in the Dominican Republic. Every month, the female trans community in Santo Domingo meets at the COTRAVETD headquarters to discuss various topics, including HIV prevention strategies, HIV treatment adherence, body issues and gender identity, romantic relationships, and how to deal with everyday situations in which family, social, or community rejection is expressed. "It's a place to talk about what you want or need to talk about," says Carlos Laureano, project assistant at COTRAVETD.



A COTRAVETD community training

The organization also trains trans health outreach workers to give lectures on HIV prevention and distribute a "battle kit" containing condoms, lubricant, and an informative flyer. In recognition of the profound need to produce real and lasting changes in the community's living conditions, COTRAVETD also organizes meetings with the trans women's partners to help them become more aware of the issues their partners are facing and prevent domestic violence.

Year 1:

COTRAVETD concluded that a meeting space and workshops promoting health access and knowledge did not have a large enough impact because many HIV-positive trans individuals did not participate in these activities or get access to the health services they needed. The organization designed its Pills for Life project, which obtained support from amfAR in 2013, to provide support for people in their homes.

The organization trained 12 trans health outreach workers to visit community members living with HIV in their own homes. Each worker is accompanied by a community volunteer who provides additional support. "To many of them, it is very hard to cope with being HIV positive and to look for help," says Carlos, who added that it is important to link this difficulty coping with HIV to the internalization of societal stigma and hostility towards trans people, sex workers, people living with HIV, and immigrants from Haiti. Often, one person embodies all these forms of vulnerability and having a safety net becomes essential for survival.

COTRAVETD also works with the Centro de Orientación e Investigación Integral (COIN), another Dominican trans organization, to provide HIV-positive people and their families with accompaniment and support when they go to get the medical services and legal advice they need.

Results:

COTRAVETD staff and volunteers have accompanied 37 trans individuals with HIV as they sought out the services they needed and many began treatment due to this peer support. "This emotional support is as, or more, important than information," says Carlos. As part of this project, COTRAVETD also organizes meetings aimed at training trans individuals to address the HIV phobias found within their community and among the general Dominican population.

Year 2:

COTRAVETD is now conducting advocacy work to promote legislative change using funding from amfAR. The organization is leading an effort to improve a draft Gender Identity Law. Regardless of if the law passes or not, the process of drafting and proposing it serves as a tool for movement building and political visibility. "It's not just a matter of whether it is approved or not," says Charles. "It is essential to put the law on the agenda for discussion and talk about the topic, so it becomes visible."

Lessons:

- Effectively caring for people living with HIV does not only involve providing them with information and access to services, but also recognizing their emotional needs.
- Peer support and, if possible, family involvement is essential to ensure that services are successfully accessed.
- Awareness raising and support work is an extended process and a one-year period is too short to produce long-term changes.
- Stigma and discrimination towards people living with HIV are not only rooted in society in general, but are also found within the community itself, and that internalization compromises the survival of people living with HIV.
- Many trans people face multiple forms of stigma and discrimination at the same time, so effective support must address all their vulnerabilities, including sex work, HIV, and nationality.
- Processes of legislative change also cause cultural change.

Silueta X

Guayaquil, Ecuador

Silueta X was founded in 2009 and legally registered in 2010. The organization works to promote legislative change, healthcare reform, and both job and sensitivity trainings for healthcare professionals and public administrators to better meet trans individuals' health-related needs. Silueta X also organizes artistic and cultural activities that provide constant communication with and visibility in the general media and social media.

Year 1:

In 2013, Silueta X received support from amfAR to carry out a project aimed at broadening the inclusion of the LGBT community in the educational system. The community has often been deprived of the right to an education due to persistent institutional discrimination based on sexual orientation and gender identity. Silueta X proposed a project to observe and analyze the educational practices of the Department of Education and provide job and sensitivity training for educational personnel at a high school in Guayaquil.

Results:

After several months of waiting for approval, the proposed educational oversight was arbitrarily suspended by the Undersecretary of District Education of Guayaquil. Silueta X filed a formal complaint with the Public Defender's Office and the Board of Citizen Participation and Accountability and ensured that the suspension maintained high visibility in the media and the LGBT community. However, the decision was not overturned, forcing a redesign of the project. Silueta X adjusted the project to focus on having a political impact by advocating for the inclusion

of LGBT in Ecuador's law to prevent and punish harassment, intimidation, and violence in schools and its law supporting intercultural education.

Year 2:

Silueta X also received support from amfAR, with additional support from Hivos, to develop a mental and physical healthcare practice that employs general practitioners, trans hormone specialists, psychologists, and nurses.

Results:

The practice not only provides trans-friendly healthcare, but also produces and analyzes the information used in the job and sensitivity trainings that Silueta X carries out at different healthcare centers in Guayaquil. Staff from the Department of Health of Ecuador evaluated the healthcare provided at the practice, in particular the hormone therapy. Silueta X plans to use the results of the evaluation to improve their own services and to advocate for better government-run health services.

Lessons:

- Relying on government representatives for a project's success can cause the project to change based on their decisions and actions, and negotiations with them should be closely monitored.
- It is necessary to react quickly and adapt work plans to the circumstances dictated by political and social factors.
- Transphobia is rooted in education and healthcare systems.



Members of Silueta X during a Kiss-In they organized on International Day Against Homophobia and Transphobia

Alfil Association

Quito, Ecuador

Alfil Association was founded in 1999 as a support organization for gay men, but has grown to include lesbians, bisexuals, and trans individuals. In 2005, the organization decided to address the impact of structural vulnerability on the trans community in Ecuador. This work involves several strategies, including advocating the government for policy changes, documenting violations of trans individuals' human rights, and providing trainings for personnel from public health institutions on how to offer trans-appropriate HIV counseling and care. Currently, Alfil's work on trans issues is focused on overcoming the obstacles to accessing healthcare faced by the trans population.



Alfil members participate in a panel.

There are many institutional barriers in Ecuador that impede or preclude trans people's access to both basic and more complex healthcare services. "Sometimes the discrimination is such that they prefer not to get medical attention even if they feel sick," says Rashell Erazo, director of Alfil Association. These negative experiences with healthcare are not only rooted in transphobia, but also in the lack of appropriate training of the professionals in charge of providing physical and mental healthcare services to trans people in health centers.

Alfil recorded the health needs of the trans community identified during two National Congresses for Transgender People that it coordinated in 2006 and 2007. Through sustained advocacy work and using amfAR support, Alfil was then able to establish training and awareness meetings for health professionals to teach them about these issues. As part of the project, Alfil also secured an agreement with the Ministry of Health in Pichincha for support establishing a clinic for trans healthcare at Alfil's headquarters in Quito.

Results:

Initially, the clinic staffed state doctors who were trained by Alfil, along with Alfil volunteers and staff. However, the doctors were not always available at the times they were scheduled. Despite the doctors' irregular availability, Alfil performed a study of the services that demonstrated the clinic's positive impact on the trans population.

With renewed amfAR funding in 2012, Alfil consolidated the clinic's hours to help ensure the doctors availability. The clinic continues to be staffed by volunteers, but now has two doctors and two psychologists who are reliably available, and it receives an average of 18 visits per week. Continued funding from and collaboration with the government helps ensure this regularity of care.

The clinic has become both a meeting place and a reference center for the trans community. It also provides concrete evidence of the positive impact good medical practices can have on the trans community that Alfil uses during its trainings of staff in government-sponsored institutions, including universities and hospitals. "Trans people are teaching them," says Rashell. Alfil also takes every possible opportunity to promote the clinic to the trans community at community gatherings and to perform outreach work, including rapid HIV testing.

Alfil had to overcome several obstacles to establish its programs, including the governments' initial resistance to sponsoring a trans-led initiative. Additionally, the government bureaucracy is often slow and ineffective, which slowed its progress. Another obstacle Alfil is still working to overcome is the negative impact of the history of institutional

violence against the trans community. "We must work to convince community members to access health services, to make their needs be addressed, and to ensure that they have spaces where they can go," says Rashell.

Lessons:

- It is necessary to constantly follow up and monitor progress when lobbying the government because apathy, indifference, and entrenched transphobia can delay and obstruct achieving the desired results.
- Effectively meeting the trans community's health needs requires both the provision of services in community spaces and training personnel in government healthcare facilities.
- The operation of a trans health clinic cannot depend solely on volunteer work, but must progress towards hiring trained, professional medical staff.
- A successful trans health clinic can provide key information to help transform practices in public institutions.

Asociación Solidaria Para Impulsar el Desarrollo Humano's (ASPIDH)

San Salvador, El Salvador

ASPIDH works to articulate the different needs of the Salvadoran trans community and advocates for government policies to ensure trans individuals' access to legal recognition of their gender identity and their rights to education and voting. The organization also provides HIV prevention and support to help trans individuals' access health services and provides trainings for and evaluations of personnel in various healthcare centers.

Year 1:

The organization was founded in 1996, but could not obtain legal status until 2009. That year ASPIDH created its own community center called We Are Healthy with support from amfAR, Pan American Social Marketing Organization (PASMO), UNDP, and the Global Fund. The center serves as a community meeting place and provides HIV prevention materials and combined HIV testing, counseling, and support services in coordination with public hospitals.



ASPIDH members promote trans healthcare rights.

Results:

Despite the center's success, in 2011 ASPIDH came to the conclusion that all the services they provide were not enough to overcome the barriers trans individuals face when accessing services, such as lack of respect for their gender identity, ridicule, rejection, hostility, and widespread ignorance about their specific health needs.

"Incredibly, many doctors, including professors, did not know what we were," says Edwin Paty Hernández, technical advisor at ASPIDH. Many trans people preferred not to go anywhere near health centers, even in situations of real need, due to the discrimination and attacks they had previously experienced from medical staff. ASPIDH decided that due to the lack of an official response to this problem, it was necessary to coordinate a community response.

Year 2:

They created a new initiative called Opening Roads that aims to train and sensitize the medical staff working with trans people in different health centers throughout El Salvador through a combination of workshops facilitated by trans people and the evaluation of services by trained members of ASPIDH who use the health services and assess the competency of the care. Those healthcare centers that pass the assessment receive an official certificate granted by the Ministry of Health that distinguishes them as a transphobia-free institution.

amfAR extended its funding of the project through its Evidence in Action program. The project also received strong support from the National Ministry of Health of El Salvador. "This work would be impossible without a cordial relationship with the Salvadoran medical system and its authorities. We could not have worked in the hospitals without their support," says Paty.

As part of Evidence in Action, a consultant was hired to develop a system to provide trainings and assess services at health centers that can be replicated throughout the country. With the help of a professional evaluator, ASPIDH did a formal base line and end line study to show whether their work in the clinics had any impact.

Results:

ASPIDH activists and trans volunteers who identify with the organization now regularly serve as the evaluating "mystery clients" and carry out the trainings and workshops. The team regularly struggles with resistance in certain health centers caused by sexism and transphobia. "Sometimes they do not want to meet us. They see us and laugh. We are pointed at. They wonder what we are going to do there and what we want, and they are slow to acknowledge that we know what we are doing, but in the end they come to realize recognize it," says Paty.

ASPIDH is currently working to overcome other challenges, including that bad past experiences with transphobic health workers continues to keep many trans people from accessing healthcare and that many hospitals and clinics only offer HIV tests in the morning, which makes the services more difficult to access, especially for sex workers who generally work at night.

The amfAR-funded evaluation enabled ASPIDH to work with other bigger donors such as PASMO and, recently, the Global Fund. "When the Global Fund asked if we could handle money, we showed our report folders. They were ashamed to have doubted. Of course we can," says Paty.

Lessons:

- Maintaining cordial relations with leadership at health institutions whose staff is being trained is important.
- Training and strengthening trans activists contributes to their recognition as experts in the health and human rights fields.
- Training and awareness need to be combined with the evaluations in order to be effective.
- Rigorous and professional management is essential for expansion and success.

Center for Information and Counseling on Reproductive Health (Tanadgoma)

Tbilisi, Georgia

Tanadgoma works to promote sexual and reproductive health and rights and HIV prevention among key affected populations, with a special emphasis on youth and mental health issues. It is also the secretariat for a sub-regional GMT network of six organizations in the South Caucasus.

In November 2010, a report summarizing an Eastern European regional meeting of GMT advocates that took place in Kiev, titled *Hidden Epidemic: HIV, Men Who Have Sex with Men and Trans People in Eastern Europe and Central Asia*, established the urgent need to develop specific HIV strategies targeting MSM and trans individuals in the South Caucasus.

Year 1:

With the support of amfAR, Tanadgoma organized the first MSM and trans conference in the South Caucasus. In order to make the conference inclusive, Tanadgoma created an experts' group to coordinate the preparation process. Almost a year after the regional report, over 30 conference participants met in Tbilisi to establish a foundation for sub-regional collaboration on the HIV response among MSM and trans individuals. Participants included delegates from Georgia, Armenia, and Azerbaijan, experts on GMT issues from Eastern and Central Europe, governmental representatives, donors, and members of international organizations.

Results:

Two main outcomes were achieved. First, the participants developed recommendations for addressing and dismantling barriers to an effective HIV response targeting MSM and trans individuals. Second, they agreed to establish a South Caucasus Network on HIV/AIDS among MSM and Transgender Individuals to implement those recommendations, including:

- Create an environment for state funding of NGO programs on HIV and STI prevention among MSM and trans individuals.
- Advocate for the government to fund and conduct regular behavioral and biological surveillance and size estimations of the MSM and trans population.
- Mobilize additional resources to improve the capacity of state institutions to meet the needs of MSM and trans individuals, in particular by training medical providers, social workers, and law enforcement representatives on MSM and trans issues and specific approaches for working with MSM and trans individuals.
- Carry out research investigating the violation of MSM and trans individuals' rights, the stigma and discrimination they experience, and their ability to access HIV prevention and treatment programs.

Year 2:

After this success, Tanadgoma realized that fulfilling the mandates of the conference required having deeper knowledge and understanding of the specific experiences of trans people living in the sub-region. With renewed support from amfAR, the organization designed a qualitative research study to document that situation and to then use the results as an advocacy tool in the three countries in the sub-region.



Regional LGBT activists from the South Caucasus at a Tanadgoma/amfAR-supported meeting to discuss trans issues

Tanadgoma designed the survey, which was approved by Georgia's National Council of Bioethics. The survey was implemented by Tanadgoma, We For Civil Equality in Armenia, and Gender and Development in Azerbaijan. Thirty trans women took the survey.

Results:

The research not only provided key information about the situation trans people face in regard to HIV. It also contributed to making their very existence visible, as well as all the different challenges they face in their family life, at school, walking in the street, trying to get a job or an apartment, and accessing hormones, surgery, and legal recognition of their identities. The development of this previously non-existent body of knowledge was one of the project's more important successes. In 2013, with support from amfAR, Tanadgoma published the report *Combination HIV Prevention among Transgender Individuals for Three Countries of the South Caucasus* in all three national languages and in English. The results include:

- Concrete protections must be put in place in the South Caucasus to stop the humiliation and violence caused by transphobia.
- Maintaining good mental health is a problem for all trans individuals in the region. Therefore, it is recommended that local and national governments provide comprehensive health services that include mental health services.
- An urgent need exists for trans-specific health informational materials and trainings to ensure that the trans community has the correct and most pertinent information regarding health and HIV.
- Healthcare workers must receive comprehensive training on addressing the health needs, including HIV issues, of trans individuals without discriminating against them. Many trans people reported being treated poorly when accessing health services, including HIV testing.
- Respondents reported a consistent and dangerous combination of vulnerability with a lack of awareness of their own rights.
- The organization is now working to develop guidelines to improve trans individuals' access to healthcare—including mental healthcare. The information gathered during this process also established a new basis to negotiate with governments and other stakeholders to create programs to improve trans healthcare access.

Lessons:

- Networks established at the sub-regional level and within each country provide a stronger, more comprehensive community response.
- Input from different types of organizations working on related issues is important when formulating an agenda and a plan to enact it.
- Trans populations are diverse and interventions need to be context-specific and tailored to their special needs to be successful.

The Institute of Studies in Health, Sexuality and Human Development (IESSDEH)

Lima, Peru

IESSDEH is a Peruvian not-for-profit organization focusing on HIV research, delivering legal services to the LGBT community, and performing artistic and cultural activism through a program called Project CiudadaniaSX. IESSDEH works in association with the Studies in Health, Sexuality and Human Development Unit (USSDH) of the Cayetano Heredia Peruvian University.

Over the last decade, it became clear to IESSDEH that it needed to differentiate programs targeting the trans population from those targeting MSM to effectively combat HIV among the trans community. With the assistance of the activist Jana Villayzan, IESSDEH then decided to acknowledge its lack of understanding of the issues faced by the trans community and seek support from amfAR.

Year 1:

IESSDEH began researching the trans population with support from amfAR in 2009. They performed a quantitative study for which 450 trans women from Peru were interviewed. The interviews were carried out by two trans women who were trained and accompanied by IESSDEH staff as they went out into different community spaces, such as beauty shops, and to private homes—at times that were convenient for the interviewee.

The study also investigated the prevalence of HIV (using rapid tests), herpes, and syphilis. The research focused on HIV in the trans population and incorporated statistical data such as respondents' level of education, employment, and access to healthcare.

Results:

- A majority of respondents reported experiencing violent and verbally abusive reactions from family members when they came out as trans.
- Due to pervasive stigma and discrimination in the healthcare sector, most trans women prefer to treat themselves and organize silicone injection parties, effectively creating a parallel health access system that is not monitored.
- Sex work is the main source of income for most trans women, which exposes them to increased risks of HIV transmission due to infrequent condom use caused by clients paying them more to have sex without a condom, by police harassing them for carrying condoms, and by sexual violence.

The study revealed strong evidence regarding the negative impacts of transphobia among trans people. "The study showed that there is a contradiction between the level of education reached by trans individuals and their poor access to employment," said anthropologist Ximena Salazar, one of



IESSDEH members in Lima

the project coordinators. The research also revealed alarming data about the community HIV prevalence: 30% of the trans community was HIV positive, while the rate among the general population was 0.4%.

The study results were published in Spanish, and then in English in the prestigious magazine *AIDS and Behavior*. The data obtained through this research became the first source of information on trans persons in Peru, and the information was used by national and international organizations, including UNAIDS.

There were two major obstacles to completing the first investigation. Previous researchers had offered the trans community in Lima financial compensation for interviews, but because this project had a clear trans leadership and limited funds, the participants agreed to do the interviews without being paid, and the high level of participation demonstrated a real interest from the community in getting involved in the project. Combining the interviews with the provision of health services and HIV testing made the project more expensive. Donations from the Barton Health Centre of the Ministry of Health and the STD Laboratory of the USSDH of the Cayetano Heredia University made it possible to provide these health services.

Year 2:

IESSDEH's second project on the trans population was a qualitative research study performed in 2012 that centered on the life stories of trans women from different areas in Peru (Lima, Ayacucho, and Iquitos). The trans interviewers trained during the first study played a central role in the development of the research. The life experiences of 11 trans women were

documented. They discussed their family and community life, their bodies and sexuality, and their access to healthcare, education, and employment. IESSDEH is currently working to disseminate the results.

One fundamental characteristic of this process was the trans community's willingness to participate. "Even when this methodology requires overcoming additional obstacles, such as the need to have more time for training, discussion, and analysis, the results prove that it is the best possible methodology for this type of project," said project coordinator Alfonso Silva Santisteban. The participation of trans activists has contributed to training community members as researchers, and they have used this experience and training to participate in other organizations' research initiatives.

Lessons:

- Trans individuals' involvement in the design, development and implementation of research projects within the trans community is fundamental.
- Community participation strategies can slow down processes; however, results indicate such participation is vital for effective research in marginalized communities.
- Funding challenges can be overcome through collaborative work.
- Training trans researchers increased community participation and increased opportunities for trans people to be employed doing future trans-related research in Peru.

Transgender and Intersex Africa (TIA)

Pretoria, South Africa

TIA is a South African organization focused on promoting trans and intersex people's human rights, including sexual and reproductive rights and their right to access comprehensive healthcare. Currently, TIA is working to extend trans access to gender affirming procedures within the existing network of primary healthcare clinics. There is a 500-person-long waiting list to receive the services through secondary and tertiary levels of care. TIA is not only advocating for policy change, but also coordinating workshops and trainings on trans and intersex health issues for health providers.

After operating in the field for four years, TIA realized that both policy change and community mobilization shared the same challenge: The lack of concrete, specific, and reliable information to support their claims about the daily discrimination faced by trans individuals. In 2013, TIA received an award from amfAR to conduct an extensive research study focused on the HIV and sexual health-related issues faced by the trans community. The researchers visited black rural areas and black townships that are usually overlooked in research efforts in the country. The research focused on trans men who have sex with men (TMSM), a key sub-population whose needs have historically been ignored. "For many people they were considered just nonexistent," states Nthabiseng Mokoena, advocacy director at TIA.

The research was conducted through focus group discussions. A total of 59 people participated in four groups in different parts of the country, including Johannesburg, Mpumalanga, Polokwane, and Mafikeng. TIA took every opportunity to introduce the research to possible participants and collect information from them, including at outreach and advocacy activities, workshops, gatherings, and conferences. TIA also conducted quantitative surveys. In total, 158 questionnaires were answered and collected from respondents from different parts of the country.



Nthabiseng Mokoena, advocacy director at TIA, role playing a press conference during an amfAR-sponsored trans advocacy exchange program in Kathmandu, Nepal.

Results:

- Exploring the situation of TMSM and getting information about them proved to be one of the most challenging issues in the process, due to the lack of previous information about

the population and to the pervasive effects of social and internalized homo- and transphobia on them. "It's very difficult for them to speak, because everyone expects them to be straight, even in the trans community," said Nthabiseng. Despite the various challenges, some key results were obtained:

- For a majority of respondents, their own definitions of 'being healthy' had little to do with sexual health and more to do with their bodies resembling the gender with which they identify.
- The public health system in South Africa is overburdened and there are limited spaces for those who want sex reassignment surgery.
- Most respondents said they were not aware of nor had they ever seen sexual health materials for trans people.
- All respondents stressed the need for trans-specific studies that do not group them with MSM.

Technological barriers were another challenge to gathering information. Only a few people answered an online questionnaire because many potential participants didn't have access to the internet. This fact convinced TIA of the need to focus on in-person interactions. TIA developed this research in partnership with COC Netherlands, which provided technical support and helped TIA develop the initial protocol submitted to amfAR.

Undertaking this amfAR-supported project strengthened TIA's management skills and provided a true learning experience in designing budgets and proposing deliverables. The process also highlighted the trans communities' special needs that were not previously taken into account in many programs targeting them. For example, prior to the research it was assumed that trans individuals had access to lube in the country, but the research proved that this was not the case.

After completing the research, TIA started working with COC Netherlands to provide lube, especially in black rural areas and townships. In 2014, TIA will continue to distribute lube to trans people in black townships and rural areas through support from COC and conduct focus group discussions on providing lube in these communities. The report on this specific project will be available in 2015.

The main success of this project was to produce community-generated data that can be used for advocacy, raising awareness about the trans community, and mobilizing trans people. It also empowered the organization and the communities involved in the process. "We learned about our community, but we also learned about ourselves," said Nthabiseng.

Lessons:

- Addressing sexual issues concerning trans populations requires intersectional approaches that involve the health, legal, and educational sectors.
- Community-driven research has a transformative effect on those involved in its production.
- Projects can be a learning experience for further planning.

Insight

Kiev, Ukraine

Insight is a feminist and queer organization led by women and trans people that focuses on political advocacy, legal support, and health activism. The organization has become one of the main advocates for LGBT rights in the Ukraine, while also working on women's and anti-censorship issues in a highly hostile environment.



Ukraine is a dangerous country to be a trans person in, not only because of the social stigma, discrimination, and violence they face, but also because of state institutionalized transphobia. According to the Order No. 60 of the Ukrainian Ministry of Health, to get legal recognition of their gender identity, trans people must be confined and examined in a mental health institution for a period of 30 to 45 days before they can be diagnosed with gender dysphoria. After that, they are allowed to present themselves before a commission of at least ten medical experts that briefly evaluates each applicant and decides on their future. Requirements for legal recognition also include coercive procedures that violate sexual and reproductive rights, such as sterilizing surgeries.

Insight provides trans people with support and counseling as they undergo this process. The organization also works to report human rights violations against trans people to different national institutions. However, the legal complaints have generally been ignored. "They say that complaints are unrealistic, fantasies of our imagination," says Timur Lisenko from Insight.

Insight received support from amfAR to counteract these arguments by designing and conducting a qualitative research study to document the realities of trans people in Ukraine and prove that discrimination does exist. "We wanted their voices to be heard, because it's not our imagination, but the true, real experience everyday, everywhere in the country," said Timur.

One of the first obstacles faced during the process was how to locate trans people willing to participate in the research in a country with high levels of social and institutional transphobia where personal disclosure is unusual. The researchers started by recruiting people involved with Insight, and then, in a process known as the snowball method—or reaching out to the original participants acquaintances and social networks—recruited 37 people from different regions of the country for in-depth, confidential interviews in a safe environment.

The interviewees explored a wide range of issues, including their relationship with their bodies, gender identities, and sexualities, their ability to access education, employment, and health services, and their families, social life, and religion. In several cases, this was the first time the interviewees told other people about the discrimination, exclusion, and violence that they struggle with in their daily lives.

Results:

During the process, Insight realized that peer-to-peer interviews with trans interviewers and respondents allowed for better, more fluid dialogues. After concluding the research, Insight analyzed the information and produced a report documenting the process and its results and began using the information in its advocacy activities. The results include:

- The majority of trans research subjects reported infrequently accessing healthcare due to the discrimination they have experienced in healthcare settings.
- There is a severe lack of qualified healthcare professionals who are suitably trained to work with trans people. The lack of specialists in hormone replacement therapy is of particular concern.
- More than half of all respondents reported being denied employment or harassed in the workplace due to their gender identity.
- The procedure to change ones gender on official identification documents is arduous and bureaucratic, and many respondents faced harassment and discrimination during this process, greatly limiting the number of trans individuals who have successfully changed the identification documents.

The research allowed Insight to build a complete database documenting trans experiences and issues, which has been used as background for the organization's advocacy and strategic litigation work and to support its visibility in the media.

In spite of the concrete evidence produced by Insight, official institutions received the research with criticism and dismissed the outcomes. Their stated reasons for not acknowledging the results included the lack of involvement of governmental experts and a weak methodology. Other institutions declined taking action based on the results to avoid any retaliation from the government.

From an organizational perspective, this project constituted a fundamental opportunity to assume community responsibility over the research and advocacy process. Conducting the research and producing the report also had a hugely positive impact on both the trans community and Insight. It strengthened community involvement with the organization, created a sense of action, and provided a safe environment for trans people to talk about their issues, revealing the healing effect of sharing personal stories with others and of learning about the similarity of other people's experiences. "It was an opportunity for them to know, for sure, that transphobia was not their fault," said Timur.

Lessons:

- Peer-to-peer research is the best methodology.
- Story-telling is a healing and empowering experience for everyone involved.
- Documenting needs and generating knowledge from within the community is an effective movement-building strategy.
- Government engagement in the process before a study is conducted might help in the acceptance of the findings.

Conclusion

The profiled organizations focused their work in four main areas: building knowledge, providing services, advocating for change, and community/movement building. For each organization, access to amfAR funding provided a great opportunity for organizational development and skills building and an opportunity to establish programs that provide meaningful and lasting change among the trans community.

The organizations that performed research produced groundbreaking community-based knowledge and data about the trans population. This knowledge, and the very process of producing it, resulted in empowerment and movement building, and put both trans issues and trans people on the map by documenting their previously ignored realities. Most of the data produced was the first official data on the trans population produced in that country.

Many of the organizations held trainings that not only educated healthcare providers and other stakeholders, but also earned the organizations recognition as experts, allowing them to multiply their interventions and reach more healthcare providers. The organizations that opened and managed trans health centers developed strategies for creating safe and friendly spaces for trans individuals that could be replicated elsewhere. Many of the organizations secured official agreements with governments to evaluate health providers and provide systematic trainings in official health settings to improve the care trans individuals receive.

Legal recognition was a central focus of most of the amfAR-funded projects—establishing a clear link between officially recognizing gender identity and providing an effective HIV response, and the organizations are continuing their work advocating for this momentous legal goal. Managing their grants also helped the

organizations improve and strengthen their operative capacity and become reliable partners for both government and international donors, and every grantee organization in the report received additional support from larger donors to continue their activities after the grant from amfAR ended.

Many of the organizations profiled were among the first organizations, if not the first organization, doing this work to improve trans individuals' rights and access to healthcare in their area. The following summarizes the challenges they most often faced, the best strategies for confronting them, and the lessons they learned.

Challenges:

- Very little formal research data or analysis on the health and human rights situation of trans people in the countries or regions existed.
- Most of the organizations operate in contexts characterized by severe social and institutionalized homophobia and transphobia, creating serious challenges to accessing and organizing trans individuals.
- Improving trans access to healthcare depended on effectively working with and advocating to transphobic and inefficient bureaucracies.
- Most trans organization had low capacity to implement research; however, they did have a good sense of how to use the data for advocacy purposes.



TIA members celebrate pride in Soweto, South Africa.



Members of COIN participate in a workshop for peer educators in Santo Domingo, Dominican Republic.

Successful Strategies:

The following is a synthesis of the successful strategies used by the organizations profiled in this report for their advocacy, research, and service delivery programs:

- Generating community-based knowledge and giving trans people the opportunity to speak about their own experiences and advocate for their rights
- Creating health centers that provide access to trans-friendly services, including emotional support services and hormone therapy
- Empowering trans people as trainers, experts, and advocates for social and legal change
- Providing trans-lead trainings to health providers, governmental officers, media, and other key stakeholders
- Negotiating with governments for partnerships, support, and provision of services
- Learning from similar experiences in other countries
- Distinguishing trans issues from MSM issues
- Producing official data on trans individuals, often for the first time

Key Lessons and Recommendations:

- Working with governments requires flexibility in dealing with unexpected and arbitrary changes, paying close attention to bureaucratic processes, and being open to political negotiation.
- Transforming policy requires data, but also developing strong personal relationships with key policy makers.
- Trans people must lead social, legal, and political processes concerning themselves. They can best access this marginalized population of their peers and best understand the issues trans individuals are facing.
- The existence of trans friendly services is not necessarily enough to convince trans people to use them. Additional sustained efforts are needed as histories of institutional violence take a long time to heal.
- Information and safer-sex kits are not enough. Trans people need access to psycho-social support as well.
- Formally documenting the situation of trans people can be transformative for the trans activists involved; however, knowledge and data alone do not bring about institutional change, as they can be questioned or denied by hostile states.
- In-depth documentation and analysis, professional management, and mid-term evaluations can expand the operative capacity of the organizations by providing a better platform to apply for additional support from funders.
- Volunteers are useful; however, having a paid staff expands and professionalizes both operations and results.
- Even when is not yet a reality, setting gender identity legislation as a future advocacy goal mobilizes trans people.

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