



## The organization of key populations connected to HIV transmission: an intervention to abate stigma; Mexico, 2005-2009

La organización de las poblaciones clave ligadas a la transmisión del VIH: una intervención para abatir el estigma; México, 2005-2009

*Cuadra-Hernández, Silvia Magali<sup>1</sup>; Zarco-Mera, Ángel<sup>2</sup>; Infante-Xibillé, César<sup>3</sup>; Caballero-García, Marta<sup>4</sup>*

<sup>1</sup>Sociologist. PhD in Sociology. Researcher of Medical Sciences, Instituto Nacional de Salud Pública, Mexico. [magali.cuadra@insp.mx](mailto:magali.cuadra@insp.mx)

<sup>2</sup>Anthropologist. Master's Degree in Social Anthropology. Honorary research fellow, Instituto Nacional de Salud Pública, Mexico. [angel.zarco@insp.mx](mailto:angel.zarco@insp.mx)

<sup>3</sup>Surgeon. PhD in Education. Researcher of Medical Sciences, Instituto Nacional de Salud Pública, Mexico. [cesar.infante@insp.mx](mailto:cesar.infante@insp.mx)

<sup>4</sup>Sociologist. PhD in Sociology. Researcher, Universidad Autónoma del Estado de Morelos, Campus Oriente, Mexico. [martacg@uaem.mx](mailto:martacg@uaem.mx)

**ABSTRACT** A qualitative and quantitative approach forms the base of this analysis of the results of "Vida Digna," a project aimed at abating stigma and discrimination in the HIV transmission field with actions taken by civil society organizations from 2005 to 2009 in the Mexican region of El Bajío. The results were analyzed in 2009 and 2010. The organizations involved were made up of key populations, defined as groups vulnerable to infection but also capable of resisting and controlling the transmission of HIV and the stigma and discrimination that are important barriers in the seeking of care and the achievement of effective HIV control. We describe and analyze the actions taken and the strengthening of the participating organizations. The visibility of new social actors such as transgender women and injecting drug users, as well as informative activities directed at journalists, the police and the military to prevent the criminalization and persecution of these groups, are highlighted.

**KEY WORDS** Non-Governmental Organizations; HIV; Stereotyping; Prejudice; Mexico.

**RESUMEN** Una aproximación cuali-cuantitativa es la base para el análisis de los resultados del proyecto "Vida Digna", cuyo objetivo fue abatir el estigma y la discriminación en el campo de la transmisión del VIH a partir de las acciones realizadas por organizaciones de la sociedad civil durante el período 2005 al 2009, en la región mexicana llamada El Bajío. Los resultados se analizaron en los años 2009 y 2010. Las organizaciones participantes estuvieron compuestas por y para las denominadas poblaciones clave, definidas como grupos vulnerables a infectarse pero también capaces de resistir y controlar la transmisión del VIH, el estigma y la discriminación, que se constituyen en barreras importantes para la búsqueda de atención y en el control efectivo del VIH. Se describen y analizan las acciones y el fortalecimiento de las organizaciones participantes. Resaltan la visibilización de nuevos actores sociales, como las mujeres transgénero y los usuarios de drogas inyectables, y las acciones informativas dirigidas a periodistas, policías y militares para evitar la criminalización y persecución de estos grupos.

**PALABRAS CLAVES** Organizaciones No Gubernamentales; VIH; Estereotipo; Prejuicio; México.

## INTRODUCTION

This article presents the results of actions taken by Civil Society Organizations (CSOs) to reduce stigma and discrimination against social groups related to the transmission of HIV/AIDS, through participation in the “Vida Digna” [Spanish for “life with dignity”] project. These actions were carried out between 2005 and 2009 in the Mexican region of El Bajío, which comprises the states of Guanajuato, Aguascalientes, San Luis Potosí, and Querétaro. This area has been historically characterized by conservative attitudes, particularly with regards to the sexual practices of social groups marginalized by hegemonic moral standards.

The National Census of Civil Society Organizations conducted by the National Center for the Prevention and Control of HIV/AIDS [*Centro Nacional para la Prevención y el Control del VIH/sida*], a Mexican governmental agency specializing in the treatment and care of this disease, indicates that there are 318 CSOs working with these issues (1), 7 of which are located in Aguascalientes, 3 in Guanajuato, 4 in Querétaro, and 2 in San Luis Potosí. On the other hand, the records of the non-governmental organization *Amigos contra el SIDA* [Friends Against AIDS] contain information on 264 organizations, 3 of which are located in Aguascalientes, 7 in Guanajuato, 4 in Querétaro, and 2 in San Luis Potosí (2).

In the case of the “Vida Digna” project, a total of 18 CSOs participated, nine of which continued their operations through 2009. These organizations were all made up of what are commonly referred to as *key populations*:

“Key populations” (KPs) is a term used by the [International HIV/AIDS] Alliance to refer to those groups which are key to the dynamics of the epidemic. KPs are highly affected by HIV due to social norms, contextual issues and sexual behaviour, or are more likely to be in a situation where they might acquire and/or transmit HIV because of their behaviours.” (3 p.3)

From its beginnings, the “Vida Digna” project encouraged the implementation of community diagnoses as a way of addressing the specific needs

of the key populations present in these jurisdictions. In all of the participating organizations, these diagnoses revealed the necessity of focusing actions on sex workers, gay men and men who have sex with men, transgender persons, and intravenous drug users (3). These groups are more likely to be exposed to HIV and to expose others to the virus, and therefore have a fundamental role in changing the dynamics of the epidemic. Specifically, the approach of the “Vida Digna” project was to place the focus on these groups in order to change the dominant paradigms of prevention and action, address the barriers of access to services, and strengthen the CSOs that promote these changes.

In Mexico, the project was led by the Positive Action program and the Colectivo Sol organization, a member of the International HIV/AIDS Alliance based in England, which organizes CSOs working to control the spread of HIV worldwide.

Stigma and discrimination form part of the cultural baggage that lead to negative associations regarding groups of people commonly linked to HIV transmission. The negative perception of those most affected by HIV stems from its association with groups historically labeled as undesirable, as in the case of some indigenous groups, gender non-conforming individuals, and/or socio-economically disadvantaged sectors (4). The processes of stigmatization translate into collective health determinants, given that they form part of the *habitus*, that is, the space in which social positions generate and reproduce practices that are:

...distinct and distinctive [...] but habitus are also classificatory schemes, principles of classification, principles of vision and division, different tastes. They make differences between what is good and what is bad, between what is right and what is wrong, between what is distinguished and what is vulgar, and so forth, but the distinctions are not identical. (5 p.19-20)

These practices influence the lack of access to health services faced by key populations, in addition to the general lack of actions aimed at prevention or the mitigation of the damage done by the disease. Infante *et. al.* (6) have documented the extent to which the knowledge, perceptions,

and practices of the staff of Mexican state health services are imbued with non-scientific notions regarding HIV transmission. This situation, coupled with negative perceptions of stigmatized groups, leads to human rights violations – for example, in relation to the confidentiality of health status and autonomy in deciding to perform the test – even when it contradicts official discourses and legislation protecting these rights. This often generates mistreatment toward patients infected with the virus, including the rescheduling or cancellation of appointments or surgical interventions (6).

Stigmatization is a social process that occurs in the context of interaction (7); it is a differentiating mechanism and is therefore relational. Regarding this system of relations in which difference is established, Bourdieu points out:

This idea of difference, or a gap, is at the basis of the very notion of *space*, that is, a set of distinct and coexisting positions which are exterior to each other and which are defined in relation to one other through their *mutual exteriority* and their relations of proximity, vicinity, or distance, as well as through relations of order, such as above, below, and *between...* (5 p.16)

It follows that stigmatizing signals are always established in relation to an “Other,” and refer to an “attribute that is deeply discrediting; [...] [hence] a language of relationships, not attributes, is really needed” (7 p.13). Thus, it can be described as a relationship between different groups wherein the difference will be based on the prevailing standards of normalcy and deviance at a given time and in a given place. What characterizes stigma, in addition to a negative connotation, is its scapegoating effect and the consensus it manages to achieve around the social sanctions applied.

Stigma deprives those who bear it of their human essence: “By definition, of course, we believe the person with a stigma is not fully human” (7 p.15). In turn, it leads to a justification of actions intended to avoid, obscure, or isolate the subject identified as anomalous:

On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce [the subject’s]

life chances. We construct a stigma-theory, an ideology to explain [their] inferiority and to account for the danger [they] represent... (7 p.15)

In the context of a medicalized society, the stigma associated with HIV transmission becomes a framework for distinguishing what is considered to be normal from the abnormal. These are forms of symbolic domination: “symbolic domination [...] is based on ignorance and therefore on the recognition of the principles in whose name it is exerted” (5 p.170). In essence its function is to maintain social control by reproducing that which is hidden. Goffman, for instance, notes that stigma can conceal other distinctions: “sometimes rationalizing an animosity based on other differences, such as those of social class” (7 p.15). The consequence is that the horrified “normal” subjects distance themselves from the anomalies, thereby strengthening the segregation that ensures social control through this discrimination. Thus, stigma and discrimination are mechanisms that complement each other and form part of what Jonathan Mann *et. al.* have called *the other epidemic* related to HIV transmission (8 p.19). This refers to a social epidemic that does not necessarily fall within the realm of biological processes, although it is anchored in a *medical viewpoint* (9): if an infected individual can transmit a disease, and if social processes are translated into biological metaphors (*morally ill* societies, made up of *ill people* suffering from the same disease, for the same reasons), then people who are *physically and socially ill* can spread this disease in all social spheres and are therefore considered dangerous. Given this, *hygienic measures* are seen as a necessity: that is, to isolate, separate, and even make the patient and the disease disappear. Behind these discrediting, isolating, and invisibilizing processes is the fear of the unknown and of that which cannot be controlled (10).

Labeling a person who is suffering from an incurable disease – one which is at times associated with *imminent death*, often leading to the decision to commit suicide (11) – entails a violation of the right to life and to dignity, provokes suffering, and produces inequities in the field of public health (12), which in turn leads to greater social inequality (13).

The “Vida Digna” project set out to put an end to these negative elements and forms of exclusion of groups associated with HIV by implementing interventions aimed at impacting policy

makers and local resources. To do so, it was determined that CSOs with an important presence in their community and that were either made up of or provided services to key populations would be in charge of fostering changes in public services at the municipal and state levels. CSOs were considered for participation whether or not they were formally registered, with special attention given to those working with health service providers, the press, and the police. In 2005, the project contacted 18 CSOs, and over the course of four years 9 CSOs stopped participating and 4 new groups were created. By the end of 2009, 9 CSOs were participating. A total of 18 CSOs participated from 2005 (the project's initial year) to 2009 (the year of the project's completion) (Table 1). The project began by conducting "participatory community diagnoses," the results of which served as the basis for the specific work plans addressing the needs of each community.

Participatory community diagnoses constitute a methodology for exploring perceptions and needs through workshops and group sessions in which various topics are addressed from participants' subjective experiences, followed by an integration of the results in open discussion. To this end, various techniques were used with participants: the creation of community maps, social and body networking, descriptions of a "typical person," a weekly or daily journal, a personal timeline, and a "key" person in their family, in addition to an assessment of the services they have access to and their healthcare needs. In all of these exercises, personal experiences related to stigmatization and discrimination surfaced. Priority was given to the results of this exploration for the purpose of generating a comprehensive diagnosis of the needs of each community, which served as a starting point for the specific activities against stigma and discrimination that the project initiated.

## METHODOLOGY

In order to detail the specific processes that took place within the organizations implementing the project, 26 semi-structured interviews were conducted with representatives of the 9 CSOs that participated in the entirety of the project,

local health service workers, and informants from key populations in the following cities: Santiago de Querétaro (State of Queretaro); Guanajuato, Irapuato, and León (State of Guanajuato); Aguascalientes (State of Aguascalientes); and San Luis Potosí (State of San Luis Potosí). Contacts were established with the aid of the organization Colectivo Sol. Qualitative data collection was conducted between October and December 2009, with a second phase to obtain additional information held in February 2010. Moreover, the organizations' 2008 work plans and 2009 quarterly reports were used as a data source via document analysis. Qualitative data was useful for detailing the processes that the CSOs underwent and for revealing the non-measurable impact of the project's actions on the populations served by the CSOs.

To carry out a comparison of the capacities of each organization (as well as the interventions in general), we began with the idea that the observed changes in the CSOs were an important indicator of the impact that the project had on the reduction of stigma and discrimination linked to HIV transmission. In other words, the results of the measurement and comparison of these capacities over time (before and after participation in the project) constitute indicators of the project's impact on each organization: if the capacities of organizations were strengthened, a positive change was achieved in abating stigma and discrimination in El Bajío, even in the case of indirect relations.

Data on modifications in capacities were obtained through two cross-sectional measurements taken in the survey: an initial measurement in 2005 and another in 2009, when the project ended. Quantitative data was collected in 2005 by the organization Colectivo Sol at the beginning of the intervention. In order to obtain quantitative data for the year 2009, an Internet-based questionnaire was designed. This questionnaire contained the same questions as the initial survey to allow for comparison, and other questions were added as a supplement. Representatives of the participating organizations were invited to participate in the survey, and each organization was assigned a unique code to enter the platform in order to safeguard the confidentiality of the participants. In addition, the online platform had a startup filter detailing the objectives of the evaluation and assuring participants that the information would be

Table 1. Organizations participating in the “Vida Digna” project by trajectory, target key populations, and main actions. El Bajío, Mexico. 2005-2009.

State	Code	Name <sup>a</sup>	Participating organizations				Target populations	Main points of action plan <sup>b</sup>
			From the beginning	Created after the beginning	Did not complete the project	Completed the project		
Aguascalientes	CSO-1	Centro de capacitación para el Desarrollo Comunitario (CECADEC)*	X			X	Sex workers	<ul style="list-style-type: none"> <li>• Sexual education from a gender-based approach</li> <li>• Promotion of Human Rights</li> <li>• Political incidence on public services</li> </ul>
	CSO-2	-	X		X		People living with HIV/AIDS	
	CSO-3	Ser Gay*	X			X	Men who have sex with men	<ul style="list-style-type: none"> <li>• Promotion of Human Rights</li> <li>• Political incidence on Human Rights and Public Services Committees</li> </ul>
	CSO-4	Fangoria Nice**		X		X	Transgender or transsexual people, transvestites, and/or sex workers	<ul style="list-style-type: none"> <li>• Promotion of Human Rights</li> <li>• Health promotion</li> <li>• Political incidence on public services</li> </ul>
Guanajuato	CSO-5	-	X		X		Men who have sex with men	
	SCO-6	-	X		X	X	People living with HIV/AIDS	
	CSO-7	Irapuato Vive*	X				Intravenous drug users	<ul style="list-style-type: none"> <li>• Syringe disinfection program</li> <li>• Sexual education promotion in syringe exchange programs</li> <li>• Political incidence on Public Services for the treatment of drug users living with HIV/AIDS</li> </ul>
	CSO-8	Transleonas**		X		X	Transgender or transsexual people, transvestites, and/or sex workers	<ul style="list-style-type: none"> <li>• Promotion of Human Rights</li> <li>• Political incidence on police associations</li> <li>• Human Rights Workshops for police and military agents</li> </ul>
	CSO-9	Colectivo Seres***		X		X	Men who have sex with men	<ul style="list-style-type: none"> <li>• Promotion of Human Rights</li> <li>• Political incidence on health services</li> </ul>
	CSO-10	León Gay**	X			X	Gay men	<ul style="list-style-type: none"> <li>• Participation in marches and forums</li> <li>• Use of Internet platforms for abating stigma and discrimination</li> </ul>
Querétaro	CSO-11	-	X		X		Men who have sex with men	
	CSO-12	-	X				People living with HIV/AIDS	
	CSO-13	Asociación Queretana de Educación para las Sexualidades Humanas (AQUESEX)*	X		X	X	Journalists, women, and the general population	<ul style="list-style-type: none"> <li>• Creation of a news network to impact the media</li> <li>• Promotion of Human Rights</li> <li>• Promotion of sexual and reproductive rights</li> <li>• Political incidence on Human Rights Committees, Education Secretariat and health services</li> </ul>
	CSO-14	-	X		X		People living with HIV/AIDS	

Table 1. Continued

State	Code	Name <sup>a</sup>	Participating organizations				Target populations	Main points of action plan <sup>b</sup>
			From the beginning	Created after the beginning	Did not complete the project	Completed the project		
San Luis Potosí	CSO-15		X		X		People living with HIV/AIDS	
	CSO-16	Fortaleciendo la diversidad***		X		X	Transgender or transsexual people, transvestites, and/or sex workers	
	CSO-17		X		X		Men who have sex with men and transgender or transsexual people, and transvestites	
	CSO-18		X		X		Men who have sex with men and transgender or transsexual people, and transvestites	
<b>Totals</b>		18	14	4	9	9		

Source: Own elaboration.

<sup>a</sup> Only the organizations that participated through 2009 agreed to publish their names.

<sup>b</sup> Only the organizations that participated through 2009.

\* Civil associations legally incorporated prior to their participation in the project.

\*\* Community-based organizations, unincorporated before 2009.

\*\*\*Civil associations legally incorporated during their participation in the project.

used exclusively for scientific purposes and that confidentiality would be maintained, unless the organization agreed to the publication of their name, thereby serving as informed consent. In 2009 ten organizations responded to the survey. Nevertheless, overall modifications in capacities that can be attributed to participation in the project can be analyzed only for the eight CSOs that participated in both surveys (2005 and 2009).

To assess changes in the organizations, four capacities were identified and analyzed as being developed through participation in the "Vida Digna" project:

1. Capacities related to internal processes of the organization;
2. Capacities associated with the development of projects on stigma and discrimination;
3. Capacities related to political incidence in the community, such as the implementation of changes to local legislation in order to increase access to health services, to reduce the police penalties for the exercise of sex work in public

places, to create programs for condom distribution in family clinics, and so on;

4. Capacities to identify the abatement of stigma and discrimination as an important part of the political actions undertaken by the CSOs (Table 2).

Each indicator was broken down into variables and assigned a score that would serve as an ideal point of comparison, thereby functioning as a Weberian *ideal type* (Table 2). For capacities 1 (related to internal organizational processes) and 3 (in which influence in the local political arena is sought), the score was binary: 1 if the capacity had been developed and 0 if not.

For indicators 2 and 4 the notion of stigma as developed by Aggleton and Parker was operationalized; that is to say, deeply discrediting attributes that are anchored in gendered, economic, racial, and sexual structures, which become even more pronounced in the context of HIV transmission (4) (Table 2). The score for these indicators was defined as high, medium or low:



- High: This score indicates that stigma is constituted by discrediting attributes and takes into account three or four of the central points identified by Aggleton and Parker (4): gender, economic, racial, and sexual inequalities and inequities. It also identifies stigma as a barrier to the development of public policies and access to services.
- Medium: Stigma is composed of discrediting attributes and refers to one or two of the points mentioned by the authors. It identifies only one barrier to the development of public policies or access to services.
- Low: Refers only to the presence of discrediting attributes, it does not identify obstacles.

For the sake of clarity, when detailing the changes attributable to the project, these scores have been converted into percentages.

Given that data from the online survey were self-reported by the organizations, a qualitative approach and periodic reviews of activity reports aided in limiting possible bias. Such mixed studies employing methodological triangulation have been gaining momentum over the past 20 years, particularly among researchers in the social sciences (16).

Overall, the mixed design was useful for collecting descriptions of the processes experienced by organizations in El Bajío, complementing and providing explanation for data on the changes in capacities.

## RESULTS

One of the most important features of the “Vida Digna” project was that it met the specific needs of each locality of El Bajío, which were determined through the application of a technique called “participatory community diagnosis” in each group’s environment. Based on these diagnoses, each CSO developed a unique action plan resulting in a variety of initiatives. For instance, in Querétaro, CSO-13 attempted a direct intervention in the media by sending news stories and comments related to homophobia, discrimination, or stigmatization of key populations to print media over the Internet. The diagnosis of this CSO resulted from a traumatic experience: the murder of one of its members and the pursuant

homophobic smear campaign, orchestrated by the state government and supported by the media and the Catholic church, aimed at justifying the shortcomings of the police investigation. This CSO also organized workshops aimed at spreading awareness of how to avoid stigma and discrimination associated with HIV and key populations, targeting local journalists and leading to the creation of a new vocabulary for reporting on issues related to HIV and key populations. Although they also developed electronic materials, maintaining their web pages was time-consuming and technically difficult to manage.

Similarly, in the states of Aguascalientes, San Luis Potosí, and Guanajuato, active organizations were created by three female leaders of the transgender community, two of which became formally registered associations – CSO-4 (a community group that continues the work initiated by CSO-3) and CSO-16 (which originated from the fusion of the organizations CSO-15 and CSO-8), which has gained recognition as a civil association. At the same time, two other organizations (CSO-4 and CSO-8) continue as grassroots collectives, with a strong presence in the community of transgender women, previously invisibilized and persecuted in their towns (Table 1).

Working with issues in the transgender community requires sustained effort on the part of the organizations. Employment opportunities for *trans girls*, as they call themselves, are scarce: hair salons, clubs and bars, or the sex work circuit. Given that they undergo physical changes it is often difficult for them to go unnoticed; they are frequently expelled from schools or simply do not enroll, given that they know from experience that it is not an appropriate place for them due to the violence they may have faced during childhood and adolescence. According to their testimonies, transgender women suffer more harassment than the gay population, given that the latter can maintain their sexual preference a secret, thereby protecting themselves from stigma:

*Gay guys do not go through any noticeable changes. If they want to, they can look like “normal” guys and that makes their chances to go to school and to get an education better than the chances we have as trans, since from the time we are kids we dress differently, speak*

Table 2. Indicators, variables, and scores assigned to evaluate the capacities of civil society organizations (CSOs). El Bajío, 2005-2009.

Indicators	Variables	Maximum score (ideal): 24
<b>I. Structures and internal processes</b>	<ol style="list-style-type: none"> <li>1. Creation of the CSO: civil association, community-based organization, or other.</li> <li>2. CSO mission and vision.</li> <li>3. Decision-making mechanisms.</li> <li>4. Accounting system.</li> <li>5. Accountability and/or audits.</li> <li>6. Organizational chart and roles.</li> <li>7. Specialized, salaried personnel working in the CSO.</li> <li>8. Inventory</li> </ol>	<b>Maximum Score (ideal): 8</b> High: 1 point. Low: 0 points
<b>II. Knowledge and capacities to develop projects on stigma and discrimination</b>	<ol style="list-style-type: none"> <li>1. Knowledge of stigma, discrimination, and Human Rights violations faced by key populations.</li> <li>2. Level of empowerment to face stigma, discrimination, and situations related to infringement of rights.</li> <li>3. Skills to manage and develop projects on stigma and discrimination.</li> </ol>	<b>Maximum Score (ideal): 6</b> High: 2 points. Medium: 1 point. Low: 0 points
<b>III Political incidence capacities</b>	<ol style="list-style-type: none"> <li>1. Development of activities with key populations.</li> <li>2. Involved in activities of State Councils for the treatment and control of HIV/AIDS, outpatient centers for HIV/AIDS and sexually transmitted diseases prevention and treatment, Human Rights State Committees, legislators or key political actors in the community.</li> <li>3. They identify the importance of some other strategies with political incidence.</li> <li>4. They recognize and make use of Participatory Community Diagnosis (PCD) tools.</li> </ol>	<b>Maximum Score (ideal): 4</b> High: 1 point. Low: 0 points
<b>IV. Identification of stigma and its relationship with political incidence.</b>	<ol style="list-style-type: none"> <li>1. Definition of stigma.</li> <li>2. Identifies stigma as a barrier to outlining public policies and to accessing services.</li> <li>3. Identifies the political incidence and relates it to the reproduction of stigma.</li> </ol>	<b>Maximum Score (ideal): 6</b> High: 2 points. Medium: 1 point. Low: 0 points

Source: Own elaboration.

*differently, move differently, and that makes schools reject us, persecute us, and then we just leave. (Informant, transgender woman)*

The lack of access to schools acts as a limit to the technical skills of this population. For instance, the data collection in this study was conducted via an online survey. However, there were many difficulties in the collecting of data from these organizations due to respondents' lack of experience working with the Internet and difficulties in reading and writing.

The accounts of representatives and beneficiaries of the organizations coincided with respect to the difficulties of working with *trans girls*, especially when they are involved in sex work circuits, an area in which social vulnerability is exacerbated by secrecy and persecution associated with these activities. Addiction, gender violence, and/or violence associated with drug trafficking complicate actions aimed at raising awareness, prevention, and control among the population of transgender women. Moreover, the hours kept by a typical sex worker, usually involving overnight

work, generally prevent them from participating in workshops and meetings during the day. This same problem negatively impacts their access to health services, prevention information, and free condom distribution, since in Mexico these services are never available after two in the afternoon. These conditions notwithstanding, several new organizations have been able to carry out systematic work with this key population, and the organization CSO-16 has been awarded the 2008 "Red Ribbon" by the United Nations in recognition of its work in this challenging field. Another organization, CSO-3, received the same award in 2010 for their continued work in the defense of Human Rights and the fight against stigmatization and discrimination faced by key populations. Currently, the three groups mentioned that work with transgender women's issues have become important actors in the development of policies related to HIV and key populations in their region. In the case of Potosí's CSO-16, sex workers and military and police forces were organized, and an agreement was reached in order to put an end to the persecution faced by sex workers.



In Aguascalientes, the collective work of the organizations CSO-1, CSO-3, and CSO-4 has resulted in major political incidence in state agencies working with Human Rights as well as in the local Congress, which has contributed to the visibility of issues affecting gay men, transgender people, and sex workers, recognizing their vulnerability to discrimination, stigmatization, human rights violations, and limited access to health services.

In the state of Guanajuato, CSO-8, which was founded as a result of the project, conducted a safer sex campaign and sought political incidence in order to change local legislation seen as stigmatizing sex workers (including transgender women) with the aim of achieving protections for their workspaces, thereby diminishing the impact of persecution on the part of police and healthcare workers. The organizations CSO-8 and CSO-10 have organized marches and events aimed at raising visibility of the issues of discrimination and stigmatization related to HIV faced by key populations. Also in Guanajuato, in the city of Irapuato, CSO-7 managed to carry out an effective syringe disinfection campaign, thereby mitigating HIV incidence among intravenous drug users, who had previously faced limited access to public health services due to the criminalization of this behavior. Resulting from peer-based outreach, the organization managed to expand access to state-run public health services in order to diagnose and provide antiretroviral treatment to intravenous drug users infected with HIV, and to halt the transmission of the virus in this population. This was the one of the first outreach initiatives targeting these groups – apart from a few experiences in northern border cities – and the first that called attention to their presence and needs in the central region of Mexico. Additionally, as part of its attempts to support other key populations, the “Vida Digna” project spurred the creation of CSO-9, an organization in the city of Guanajuato working to provide services to gay men, a group that was previously underrepresented in city social services. Furthermore, raising the visibility of the gay male population in the city of Guanajuato strengthened the effectiveness of condom distribution campaigns and raised awareness among healthcare providers of issues of discrimination, particularly regarding access to rapid HIV testing and/or antiretroviral treatment.

The capacities of eight participating organizations were compared via data obtained from two surveys conducted in 2005 and 2009 (Table 3). This comparison was used to measure aggregated capacities improved by the project, that is to say, the skills developed by the “Vida Digna” project. These calculations were performed with data from the eight organizations that had both initial (2005) and final (2009) measurements.

The qualitative approach revealed that organizations clearly identified certain political actors to form relationships for the purpose of establishing partnerships and influencing public policy. Furthermore, the organizations achieved an awareness of the importance of planning long-term, externally funded projects:

*I think this project that should be continued, because [...] it's given cohesion to all of the civil organizations. The resources it provides help to unify the work we do. If some source of funding is lost, organizations might start to break up and lose the progress that they've made. (Informant, CSO-9, Guanajuato)*

Moreover, the project had a major impact on improving the visibility of stigmatized populations as well as access to health services that were formerly denied to these groups due to stigmatization:

*Now doctors will properly examine gay people in their offices, whereas in the past they wouldn't have even touched them. The fear of accidental exposure was more widespread, especially among nurses, but now it's less common and easier to pinpoint and address. (Informant, CSO-3, Aguascalientes)*

The violence associated with the discrimination against key populations may also have been mitigated by this project. According to respondents, a positive influence in the general population has been achieved:

*Since [CSO-16] has been functioning things have changed for the better [where we work]. If [the organization] were not running, anyone could come around and treat us as they pleased. [...] In the past, there was a lot of*

Table 3. Comparison of participating organizations' capacities. El Bajío. 2005-2009.

Code	Name	State	Capacities 2005						Capacities 2009					
			I	II	III	IV	Ideal Score: 24	% Skills developed	I	II	III	IV	Ideal Score: 24	% Skills developed
CSO-9	Colectivo Seres	Guanajuato	8	5	2	3	18	75.0	8	6	4	5	23	95.9
CSO-13	AQUESEX	Querétaro	7	2	3	4	19	79.2	7	6	4	5	22	91.7
CSO-3	Ser Gay	Aguascalientes	3	4	4	5	16	66.7	7	6	4	5	22	91.7
CSO-7	Irapuato Vive	Guanajuato	7	5	3	3	18	75.0	7	6	4	3	20	83.3
CSO-1	CECADEC	Aguascalientes	6	5	3	4	18	75.0	6	6	3	5	20	83.3
CSO-14	COIVHIS	Querétaro	0	0	0	4	4	16.7	4	5	4	4	17	70.8
CSO-4	Fangoria Nice	Aguascalientes	2	3	1	0	6	25.0	2	3	3	4	12	50.0
CSO-8	Transleonas	Guanajuato	0	3	2	0	5	20.8	2	3	3	3	11	45.8
<b>Totals</b>			33	30	18	23	104	54.2	43	41	29	34	147	76.6

Source: Compiled by the authors from initial survey of the "Vida Digna" project (2005) and the online "Vida Digna project evaluation" survey (November 2009-February 2010). Cuernavaca, Morelos, Mexico.

Note: Data from CSO-10 and CSO-16 are not included in order to respect parameters of comparison.

I = Structure and internal processes. II = Knowledge and skills to develop projects on stigma and discrimination. III = Capacity for political incidence. IV = Identification of stigma and its relation to political incidence.

AQUESEX = Asociación Queretana de Educación para las Sexualidades Humanas. CECADEC = Centro de Capacitación para el Desarrollo Comunitario. COIVHIS = Centro de Orientación e Información de VIH/sida.

*disrespect, people called us names, they tried to humiliate us, they would throw trash, beer cans, bottles at us, they would even try to grope us. But since [CSO-16] has been around, everything has changed, because now if a patrol car passes by and there is some drunk around trying to bother us, the police support us; in the past that didn't happen, they would just pass us by. All that kind of discrimination is over now, we suffered a lot of discrimination, they discriminated against us a lot, but now they respect us. We've been able to have talks, with Censida, with [the organization]. (Sex worker, San Luis Potosí)*

The project also diminished – although perhaps only temporarily – one of the most pervasive problems with violence faced by key populations in Mexico, particularly those participating in sex work circuits: military and police harassment.

*Two years ago two of my girls were beaten by the police. At the bar entrance, they wouldn't let them pass [to the Zone of Tolerance]: "don't go in," "I'm just going to ask [the bar owner] for money for a taxi." They*

*just wanted me to give them money for a taxi, but they would not let them pass, they beat them, they beat them very, very badly. I was very angry. And I thought that I shouldn't let them get away that. Listen, fortunately [CSO-1] arrived at a good time. They gave me some guidance and I started to defend myself more. [The police] saw that, because when they arrived and they saw [CSO-1] they began to stop violating our rights, to stop discriminating against them. For example, before they told the girls, "if you didn't bring your test results, go home, you can't work." But now it's different, if you don't bring your photos, for example, there's no problem, next week. They are more willing to talk to us. There's communication now. They let them out [of the Zone of Tolerance]. [CSO-1] showed us how to defend our girls and our rights. (Bar owner, Aguascalientes)*

The quantitative approach allowed us to document and measure improvements in the capacities of the eight organizations that responded to the surveys in 2005 and 2009 (Table 3). CSO-9, which was founded after the project began, saw

the most improvement (increasing from 18 points in 2005 to 23 points in 2009). Although CSO-4 and CSO-8 scored at the bottom (6 to 12 and 5 to 11 points, respectively), they still represented an important change given that these organizations serve the population of transgender women, a group that was previously not represented in civil society organizations related to the control and prevention of HIV. By grouping capacities together (Table 4), a comparison of the results from 2005 and 2009 show general improvement attributable to the project. The most developed capacity was political incidence (which grew from 18 to 29 points), followed by the development of knowledge and skills for creating projects on stigma and discrimination (from 30 to 41 points), the importance of identification and reduction of stigma via public policies (23 to 34 points), and finally the strengthening of structures and internal processes (33 to 43 points). Collectively, these capacities improved from a score of 104 to 147 points (Table 4).

## CONCLUSIONS

Although the project improved the four main capacities for reducing stigma and discrimination (from 54.2% in 2005 to 76.6% in 2009) among the organizations of El Bajío by raising the visibility of historically stigmatized groups and working to achieve political incidence at both the state and national levels, it had less success with the development of measures to strengthen the internal structures of organizations. Limited progress in this area has implications for the viability of long-term actions aimed at reducing stigma and discrimination, given that the consolidation of the internal structure of organizations can lead to external recognition, especially by government bodies or public agencies, affording the organizations access to funding for specific interventions and allowing them to continue operating even after the project has ended.

### Organizations of transgender people involved in sex work

One of the most notable achievements of the project was its role in consolidating the work of

the three organizations that focused their actions on transgender people, perhaps the group facing the most negative identification and discrimination due to practices associated with bodily changes and participation in sex work circuits. All of the organizations focusing on these groups were created under the impetus of the project, led by transgender women involved in sex work circuits. CSO-4 and CSO-8 greatly increased their capacities despite severe limitations due to the stigmatization and discrimination they have historically faced. These positive changes notwithstanding, it should be noted that these two organizations have not managed to become legally registered and therefore run the risk of failing to achieve political incidence and disbanding without having stimulated structural changes regarding stigma and discrimination. Moreover, qualitative analysis indicated that CSO-16, a legally registered organization, contributed to the creation of new niches for people participating in sex work circuits, a group that has historically faced limited employment opportunities and increased vulnerability to poverty and exploitation due to stigmatization. Therefore, we contend that the legal recognition of organizations may also contribute to employment opportunities

Table 4. Overall performance in interventions to abate stigma and discrimination. El Bajío, 2005 and 2009.

Capacities	Scores		Percentages	
	2005	2009	2005 %	2009 %
I. Structure and internal processes. <b>Maximum score: 64</b>	33	43	51.6	67.2
II. Knowledge and skills to develop projects on stigma and discrimination. <b>Maximum score: 48</b>	30	41	62.5	85.4
III. Capacity for political incidence. <b>Maximum score: 32</b>	18	29	56.2	90.6
IV. Identification of stigma and its relation to political incidence. <b>Maximum score: 48</b>	23	34	47.9	70.8
Totals <b>Maximum score= 192</b>	104	147	54.2	76.6

Source: Compiled by the authors from initial survey of the "Vida Digna" project (2005) and the online "Vida Digna project evaluation" survey (November 2009-February 2010). Cuernavaca, Morelos, Mexico.

available to certain groups marginalized in the labor market.

### **Knowledge on stigma and discrimination: obstacles to putting it into practice**

In general, all organizations had clear working definitions of stigma and discrimination. Additionally, representatives of the organizations that participated through 2009 clearly indicated that the project helped them to rebuild their own identity from a non-stigmatized perspective, given that many of the leaders were also beneficiaries of their own organizations. Nevertheless, qualitative data revealed that all of the organizations noted that they have not been able to fully overcome homophobia coming from diverse groups. Although participants in the project were able to identify major pre-existing stigmas, they were not able to differentiate as clearly between the different forms of stigma and put into practice specific interventions to reduce them, which in turn resulted in fragmentation of the joint actions coordinated by organizations of the same region.

### **Indicators of assessment and mobility of organizations**

The project proved to be an effective intervention in terms of the strengthening the participating CSOs: it consolidated some and created others. Nonetheless, data collection and comparison of results proved difficult, due to the diversity of the actions carried out by organizations. This calls attention to the importance of developing methods and techniques for keeping records on a variety of interventions and their impact from the beginning of their implementation that can also account for their specificities. The use of information technology and the Internet proved advantageous, indicating that it is necessary to review and evaluate potential uses for similar projects.

On the other hand, there was a notable mobility on the part of organizations participating in the project during its five years of operation. Of the 14 initial CSOs, five remained active throughout the course of the project, one participated intermittently, and four new organizations were founded.

The evaluation revealed that in most cases the disbanding of CSOs was attributable to a tendency of key populations to remain undercover, which conflicted with the project's objective of raising visibility. A discussion of this contradiction cannot be ignored in any intervention involving stigmatized and/or criminalized groups.

The need to assess changes in knowledge, perceptions, and practices of healthcare providers working with these populations suggests that it might be appropriate to apply short, pre-validated questionnaires on stigma and discrimination to those providers.

In summary, the evidence gathered in this assessment seem to indicate the following regarding interventions aiming to abate stigma and discrimination:

1. Their success stems from the participation of organizations created by and for members of civil society. Peer-based work, as in the case of actions conducted with intravenous drug users, contributes to increased levels of trust on the part of difficult to access or invisibilized populations and can have political impact in terms of building programs to meet their specific needs.
2. They must be sustained by strategic plans designed to direct the work of the organizations. The strengthening of the organizations' internal processes and their formal recognition represent important elements to ensure their viability.
3. They entail the construction of process-based indicators that allow for comparability but at the same time account for the specificity of programs that address particular situations, as in the case of the "Vida Digna" project. Stigma and discrimination take on different forms in different contexts, and therefore the construction of indicators to assess their impact presents the challenge of creating standard measures that do not erase the specificity of each situation.
4. They require technical capacities for Web-based information management. The advantages of so-called "social networks" must be taken into account in order to reduce the costs of communication and promotion of activities, thus enabling the organizations to allocate more of their resources to the abatement of stigma and discrimination rather than the maintenance of costly websites.

5. It is clear that the organizations must develop an understanding of the dynamics of local leaders, the internal organization of health services, and the media in order to carry out more specific and efficient political interventions. Notions of the structure of institutions, the construction of leadership networks, and coordination of functions are all necessary depending on the type and level of political incidence desired. That is, an intervention targeting the internal policies of hospitals related to the care of key populations will differ from a proposal in the legislative sphere to design policies aimed at reducing stigma and discrimination.

Finally, we suggest that groups participating in interventions – particularly those that result in the creation of new organizations serving highly stigmatized populations – should share experiences regarding the implications of converting key populations into CSO representatives. The creation of CSOs allows for the opening of new niches in the job market for groups whose opportunities are limited, as demonstrated by the case of organizations working with sex workers. However, this must be combined with demands to recognize sex work as legitimate formal employment, implying rights and obligations of the people participating in this activity. The right to citizenship should guide this reflection, which does not always occur in Mexico.

---

## ACKNOWLEDGEMENTS

This study would not have been possible without the trust and support of the International HIV/AIDS Alliance and the Positive Action program, the international organizations that funded the “Vida Digna” project. The Colectivo Sol organization was one of our most important resources in this assessment. Juan Jacobo Hernández and César Coria and his team provided us with all information in a timely, transparent, and kind manner. Furthermore, we would like to acknowledge the efforts of our expert in database design, César Meza Carrillo, as well as the help of Carolina Becerril and Ruy Caseb Aron. The CSOs participating in the “Vida Digna” project deserve a special mention. We would like to express our sincerest appreciation for their tenacity and commitment to the abatement of stigma and discrimination.

---

## BIBLIOGRAPHIC REFERENCES

1. Centro Nacional para la Prevención y Control del VIH/Sida. Gráficas del Censo Nacional de las Organizaciones de la Sociedad Civil [Internet]. México: CENSIDA; 2011 [cited 4 Oct 2011]. Available from: [http://www.censida.salud.gob.mx/descargas/osc\\_conv/graficas\\_censo.pdf](http://www.censida.salud.gob.mx/descargas/osc_conv/graficas_censo.pdf).
2. Amigos contra el Sida AC. Listado general [Internet]. México [cited 4 Oct 2011]. Available from: [http://www.aids-sida.org/archivos/directorio\\_nacional/listadogeneral.html](http://www.aids-sida.org/archivos/directorio_nacional/listadogeneral.html).
3. Prance R. Final Report to GlaxoSmithKline Positive Action Programme: Vida Digna phase 2: reducing HIV/AIDS-related stigma and discrimination in Mexico, January to December. Alliance International HIV/AIDS; 2008.
4. Aggleton P, Parker R. Estigma y discriminación relacionados con el VIH/SIDA: un marco conceptual e implicaciones para la acción. México DF: El Colegio de México; 2002. (Documento de trabajo No 9).
5. Bourdieu P. Razones prácticas. Sobre la teoría de la acción. Barcelona: Anagrama; 1994.
6. Infante C, Zarco A, Cuadra SM, Morrison K, Caballero M, Bronfman M, Magis C. El estigma asociado al VIH/SIDA: el caso de los prestadores de servicios de salud en México. *Salud Pública de México*. 2006;48(2):141-150.
7. Goffman E. Estigma: La identidad deteriorada. Buenos Aires: Amorrortu; 2001.
8. Mann J, Gostin L, Gruskin S, Brennan T, Lazarini Z, Fineberg HV. Health and Human Rights. *Health and Human Rights*. 1994;1(1):6-23.
9. Foucault M. El nacimiento de la clínica: Una arqueología de la mirada médica. México DF: Siglo XXI Editores; 2001.
10. Cuadra SM, Infante C, Zarco A, Morrison K, Bronfman M. Reporte cualitativo sobre el estigma y la discriminación relacionados con las personas que viven con VIH: el caso de los proveedores de servicios de salud. Cuernavaca: CISS/INSP; 2003.

11. Cuadra SM. Vulnerabilidades para la transmisión del Virus de Inmunodeficiencia Humana en contextos de movilización: mujeres en trabajo sexual de Chetumal, Quintana Roo. [Tesis de Doctorado]. México DF: Facultad de Ciencias Políticas y Sociales, Universidad Autónoma de México; 2012.
12. Whitehead M. The concepts and principles of equity and health. Copenhagen: World Health Organization; 2000.
13. Silva LV, Almeida NF. Equidade em saúde: uma análise crítica de conceitos. Cadernos de Saúde Pública. 2009;25(Supl 2):S217-S226.
14. Rawls J. La justicia como imparcialidad. In: Teoría de la justicia. México DF: Fondo de Cultura Económica; 1995. p. 17-61.
15. Cortina A, Martínez E. El ámbito de la filosofía práctica. In: Ética. Madrid: Editorial Akal; 1996. p. 9-28.
16. Greene JC. Is mixed methods social inquiry a distinctive methodology?. Journal of Mixed Methods Research. 2008;2(1):7-22.

---

#### CITATION

Cuadra-Hernández SM, Zarco-Mera A, Infante-Xibillé C, Caballero-García M. The organization of key populations connected to HIV transmission: an intervention to abate stigma. Mexico, 2005-2009. Salud Colectiva. 2012;8(2):191-204.

Received: 24 June 2011 | Revised: 4 October 2011 | Accepted: 28 October 2011



This work is licensed under the Creative Commons Attribution-NonCommercial 4.0 International License. Attribution — You must attribute the work in the manner specified by the author or licensor (but not in any way that suggests that they endorse you or your use of the work). Noncommercial — You may not use this work for commercial purposes.

The translation of this article is part of an interdepartmental collaboration between the Undergraduate Program in Sworn Translation Studies (English < > Spanish) and the Institute of Collective Health at the Universidad Nacional de Lanús. This article was translated by Diego Bray, reviewed by Pamela Vietri and modified for publication by Joseph Palumbo.