

Multi-Sector Participation in the National Response to Prevent and Address the HIV/AIDS Epidemic in the Republic of Cuba, 2007-2008

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Abstract

The development of a strong national response involving multiple sectors—including civil society—is an essential aspect of the social management of the HIV/AIDS epidemic. The goals of this response are to control the epidemic and improve the quality of life for people living with HIV/AIDS (PLWHIV/AIDS); this includes combating stigma and discrimination, as well as ensuring due compliance with the law. Cuba has a national program to prevent and control HIV/AIDS. Since 2003 Cuba's national program has received material and financial support from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Program evaluation is carried out by an independent team at ENSAP (National School of Public Health). This paper reports on results of one part of that evaluation: an assessment of the agencies and sectors who made up the organized social and national response to the HIV/AIDS epidemic. The evaluation primarily used qualitative analyses of the activities and tasks proposed by sectors in their 2006-2008 work plans. Visits were made to the provinces of Ciudad de la Habana, Matanzas, and Holguín. Qualitative techniques included in-depth interviews, semi-structured interviews, observation, and review of documentary evidence of all kinds (videos, reports, minutes, protocols, results of social research, and

radio broadcast messages) and varied depending on the particular features of each sector. We noted improvements in multi-sector participation to prevention and response to the national HIV/AIDS epidemic. Conscious of their role in preventing and controlling the epidemic, sectors generally carried out their programmed activities and had improved their organization, planning, and systematization; integration among the sectors was also better. These local initiatives provided evidence of a multi-sector response characterized by autonomy, emotional involvement, and an identification with the goals of the project; this went beyond simply meeting targets. Cross-sector work showed a marked increase and a qualitative leap in management compared with the previous evaluation. Interviewees from different sectors all considered discrimination and stigmatization of people living with HIV to have decreased, both within their organizations and in the general population.

Key words: Social participation, Multisectorality, HIV/AIDS

Introduction

In late 1986 the Republic of Cuba established a national HIV/AIDS prevention and control program based on four clearly-defined components: epidemiologic monitoring, health promotion/education, medical care, and research. Other aspects of the program included training, program evaluation and the creation of a network of laboratories. The national program systematically tracks and evaluates a strategic development plan involving those state agencies, governmental institutions, and NGOs which act as part of the effort to reduce HIV infection.^{1,2}

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The HIV/AIDS epidemic in Cuba has been characterized by a low level of transmission with a slow but sustained growth rate. The prevalence rate at the end of 2008 was 0.08% for all ages and 0.13% among 15-49 years olds; this was slightly above the prevalence in 2007. Between 1986 and September 2009 11,631 people were diagnosed with HIV; 9,606 of them were persons living with AIDS (PLWAs). The epidemic was initially imported but subsequent cases resulted from in-country transmission. In Cuba HIV is primarily a sexually transmitted infection occurring in men, 88.04% of whom are men who have sex with men (MSMs). A small increase in transmission in women has been noted.³

In 2003—at the joint initiative of the Cuban Government and the United Nations Development Program (UNDP)—a program entitled “Strengthening the multi-sector national response to prevent and address the HIV/AIDS epidemic in the Republic of Cuba” was created with financing from the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). This project provided both material and financial aid for a multi-sector response. Program activities started the same year. Since the inception of the project, teams of researchers from the National School of Public Health (ENSAP) have made independent project evaluations for purposes quality control and as a way of validating program outcomes for international agencies.

The multi-sector national response (MNR) was designed to involve diverse social sectors in joint actions to reduce the HIV/AIDS epidemic in the country. Multi-sector participation enhances capacity for social response and collective responses which promote healthy sexuality, risk prevention, comprehensive care, and social inclusion for those affected by the disease.

The development of a strong national response involving multiple sectors—including civil society—is an essential aspect of the social management of the HIV/AIDS epidemic. The goals of this response are to control the epidemic and improve the quality of life for people living with HIV/AIDS;

¹ “Antecedentes” Programa Nacional de Prevención de VIH/SIDA. Available at: <http://aps.sld.cu/bvs/materiales/programa/prosida.html>

² República de Cuba. Plan Estratégico Nacional ITS/VIH/SIDA, 2001-1006. Available at: <http://www.sld.cu/galerias/pdf/estrategia.pdf>

³ Registro informatizado de VIH/SIA.2008/09. MINSAP, República de Cuba

this includes combating stigma and discrimination, as well as ensuring due compliance with the law. Intersectorality—the coordinated intervention of institutions representing different social sectors in actions addressing issues of health, welfare, and quality of life—is an important part of this organized social response. It involves converting informal or chance cooperation into actions which, led by the health sector and backed by duly agreed national or local policies, strategically address problems which have been identified and prioritized and in which the activities of other sectors can be influential.⁴

Multi-sector participation was supported by this project and—due to its reach within civil society—was considered capable of impacting on this important socio-medical problem.

Raising awareness among the various social sectors about the need to combat the epidemic implies dedicated educational work with management, employees, and workers. They need to understand the socio-medical and legal aspects of the disease as well as how to promote prevention. Certain attitudes and discriminatory practices which persist in various work environments need to be changed. Putting legislation into practice should lead to non-discrimination in a healthy work environment; this supports the human rights of people living with HIV.

The purpose of this evaluation was to alert those responsible for overseeing the project—both in Cuba and at the funding body—of any shortfalls in reaching the project’s overall national goals. This paper presents data on one of the five goals examined during the most recent evaluation: the responses of each sector to questions concerning project activities:

- Did the sector contribute to strengthening the MNR response to the epidemic?
- How did the sector implement the MNR?
- What was the importance, relevance and quality of actions carried out in the areas of interest?
- Was there discrimination and stigmatization within or outside of the sector?
- Was current legislation implemented and complied with?

Objectives:

To evaluate the outcomes achieved by agencies and sectors involved in the MNR project as an ex-

⁴ Castell-Florit Serrate P. La intersectorialidad en la práctica social. La Habana: Ciencias Médicas; 2007

pression of the organized social and national response to the HIV/AIDS epidemic in 2007-2008.

Specific objectives were:

- Determine the project’s effectiveness in reinforcing and extending the national response to the HIV/AIDS epidemic.
- Verify fulfillment of target indicators and activities planned by the agencies involved in the selected territories.
- Identify the empowerment and participatory capacity of different social sectors engaged in the MNR.
- Identify any changes in the extent to which PLWHIV faced stigmatization and discrimination.

Methodology:

This participatory evaluation was based on a qualitative analysis. It focused on progress made in achieving the tasks proposed by each sector in its work plan for the period under evaluation. Actual results were determined by direct observation and other evidence examined at the local sites. The evaluation looked at potential project impact. Figure 1 summarizes the various components of this methodology.

Information was obtained in each sector via in-depth interviews, semi-structured interviews, observation, and review of documentary evidence. Documentary evidence included a variety of media—videos, reports, minutes, protocols, social research results, radio messages— and depended on the particular features of each sector.

Information was obtained from a variety of sec-

ondary sources. These included the epidemiological monitoring reports produced by the National Statistics Office (ONE), national and non-governmental statistical information associated with the project (primarily the National STI/HIV/AIDS Prevention and Control Program), and other reports and documentary evidence provided by the different sectors.

The data collected using these qualitative and quantitative techniques were analyzed by triangulation methods. This was done to assure that findings were consistent and thus, that our final conclusions were valid. This process involved a number of steps:

- Precise characterization of the outcome to be measured.
- Adaptation and/or creation of instruments for data collection.
- Selection of key informants. These included anyone whose involvement in the project meant they had information the researchers felt was potentially relevant.
- Organization and scheduling of fieldwork. This was done in coordination with the institutions and sites selected for review.
- Review and analysis of documents, including project evaluation reports by the National Statistics Office (ONE) and other involved sectors and institutions.
- Data processing. Specific methods depended on which instruments were used.
- Analysis, interpretation, and evaluation of outcomes.
- Drafting preliminary and final reports with con-

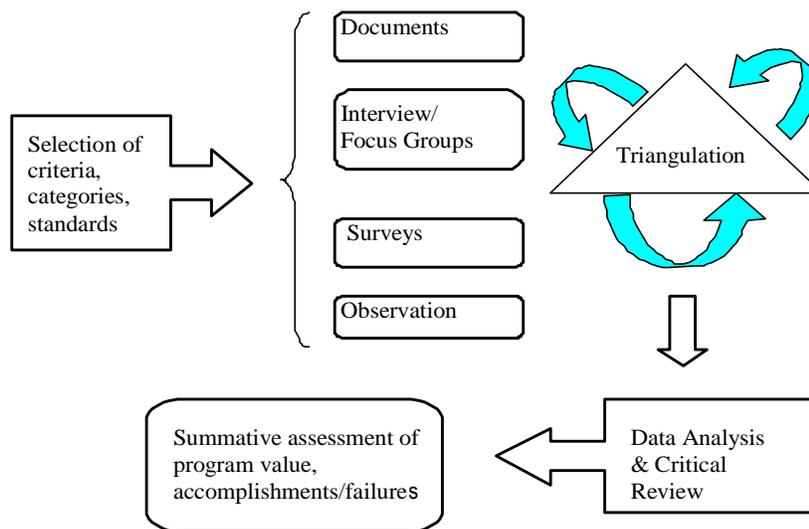


Figure 1. Summary of methodology

clusions and relevant recommendations.

The analysis included comparisons—where germane—of outcomes and recommendations with the baseline assessment which had been made prior to the period under study. There was also an appraisal of how well the targets and standards set by the project had been met. All sectors had been duly informed of the role of ENSAP as an independent evaluator.

The analysis was undertaken based on established terms of reference: what was to be evaluated, what methodology was to be used, and expected products.

We evaluated the provinces of Havana, Matanzas and Holguín. These provinces had been evaluated the previous year because of their importance in terms of HIV/AIDS cases and the number of actions undertaken with support from the project; these were the basic selection criteria for the current evaluation phase. In each of these provinces we evaluated outcomes in the same municipalities which had been studied previously.

The analytical categories guiding the evaluation were:

- Presence and knowledge of the master plan outlining the MNR.
- Local awareness of MNR activities at the national and territorial level.
- Evidence of a plan for local activities and tasks.
- Overall evaluation of completed activities.
- Assessment of completed activities (including the training of students, workers, and specialists at different levels) according to specific criteria.
- Local perception of the existence of discrimination and stigmatization within and outside the sector.
- Available resources and their maintenance.
- Initiatives undertaken as part of the project.

For the Ministry of Labor and Social Security (MTSS) we evaluated:

- Implementation of and compliance with current legislation.
- Employment policy claims.
- Monitoring of those receiving Social Security benefits.

For the National Center for Medical Informatics (Infomed), we evaluated:

- Existence and use of digital resources about HIV/AIDS.
- Degree to which the territories' health institutions were connected to the Infomed network.

Outcomes were analyzed in two phases. During an initial, intensive phase we looked at what was happening in selected areas within each sector at the national, provincial, and municipal levels. During the second phase we attempted to combine the work of the various sectors. An extensive report on Phase 1 has been prepared previously; this paper reports on phase 2. Synthesis with phase 1 results allowed us to identify shortcomings and make recommendations.

Measures were taken to assure all data was kept confidential.

Participants

The following sectors participated in the evaluation:

- Centro Nacional de Prevención de ITS/VIH/SIDA (National Center for the Prevention of STD/HIV/AIDS, CNP)
- Centro Nacional de Educación Sexual (National Center for Sexual Education, CENESEX)
- Centro de Estudios sobre la Juventud (Center for the Study of Youth, CESJ)
- Instituto Cubano de Radio y Televisión (Cuban Institute of Radio and Television, ICRT)
- Ministerio de Trabajo y Seguridad Social (Ministry of Labor and Social Security, MTSS)
- Ministerio de Educación Superior (Ministry of Higher Education, MES)
- Centro Nacional de Información de Ciencias Médicas (National Center of Medical Informatics, Infomed).

Results

Sectors

We were able to verify links between the national strategy for tackling the HIV/AIDS epidemic and the social mission of the agencies involved in the project. There were strategic plans at the central, provincial, and municipal levels for the promotion of sexual health, prevention of risky behaviors, and non-discriminatory care of people with HIV. Social sectors had examined their role in this health problem and created an organizational response that was implemented down to the municipal level; this is illustrated in Figure 2. Several examples demonstrate this process:

The Ministry of Labor and Social Security created the necessary human and technical infrastructure to train its employees about HIV/AIDS; updated current legislation on employment, safety and social welfare at the national level; and organized a

sectorial response which heightened the awareness, mobilization, and training of management and workers.

Under the banner “Let Social Work provide hope”, the Center for the Study of Youth included HIV/AIDS in the curriculum of the four social work schools and its own municipal offices. Management groups were empowered to run training sessions at the provincial and municipal levels. Students throughout the country demonstrated creativity in this educational work.

The Ministry of Higher Education initiated university outreach work at the country’s 17 universities and the Ministry’s municipal offices. The MNR project was incorporated into its comprehensive strategy for promotion of healthy living. This approach proved effective, not only because it provided material support, but also because the program’s actions were formalized, developed, and recorded. These activities became integrated into the criteria for evaluation of the institution’s management.

CENESEX revitalized the sex education curriculum at medical schools in the five selected provinces. This led to training of management groups, the formalization of an elective course for medical students, and the training of promoters in sexual health. These promoters subsequently worked with communities and risk groups.

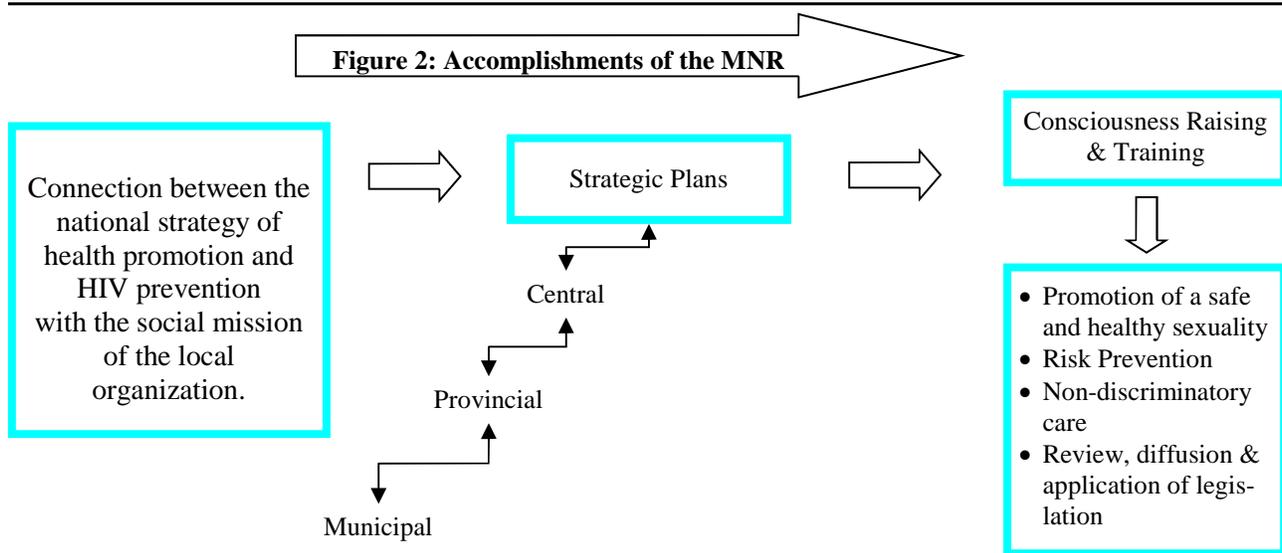
The National Center for Medical Informatics made a profound impact by providing interested professionals with access to specialized information on HIV/AIDS. The Center created a virtual thematic library on HIV/AIDS, prepared and distributed digital collections on CD, published a monthly supplement on AIDS as part of the Bibliomed Bul-

letin, and trained librarians as promoters. Visits to the Infomed website were 116.5% greater than the plan’s target; this speaks to the number of interested users who took advantage of this technological resource. The number of visits has now stabilized at a value higher than predicted. Other information resources have been incorporated which broaden the content beyond what had initially been planned. There have been laudable initiatives such as Bibliosida (an AIDS library) created for teenagers and young adults in the town of Plaza de la Revolución. It was gratifying to hear the program’s directors discuss what they had learned from various radio and television stations. They demonstrated correct use of terminology, had accurate information on various aspects of the infection, were aware of the current local issues, and were motivated to increase the number and quality of activities.

The strategies for action chosen by sectors to implement project activities and tasks depended on the particularities of epidemic in each territory and on local socio-economic and cultural specificities; this meant that program activities were adapted to local conditions and the role of the agency in the community.

The evaluation team concluded that the achievement of program objectives would have a broad social impact. The various social actors had the ability to change public opinion given their social mission and their ability to affect popular ethical and moral values. This could be done through radio and television, the labor and social security system, universities, medical schools, the medical information web portal (Infomed), and the social work schools.

The ONE⁵ survey, for example, found that



73.3% of 15-34 year olds reported they got information about HIV/AIDS from the radio and 98.2% from television. The most frequently cited television programs were the soap opera *La Cara Oculta de la Luna* (The Dark Side of the Moon, watched by 95.3%), *Hablemos de Salud* (Talking about Health, watched by 91.8%), *Cuando una Mujer* (When a Woman, watched by 78.2%) and “spots” (seen by 74.4%). An additional advantage of these programs was the discussion of HIV/AIDS within the context of homosexuality and bisexuality.

Compared to the prior evaluation, there had been a qualitative leap in project accomplishments. There was evidence of greater organization, systematization, autonomy, and creativity in both executing the project plan and in carrying out projects based on local initiatives. Awareness of the need for sectoral and cross-sector action was judged to be acceptable. There was strong commitment to developing and completing MNR tasks in all the agencies visited. Attitudes were less prejudicial and discriminatory. Radio and TV staff showed better awareness of and involvement in the project. In Matanzas the staff of Radio Banes noted with pride, that they:

had been able to use radio messages to debunk myths about the treatment of MSMs, to come to know their spaces and preferences, to enter their world”...

Actions to prevent and address the HIV/AIDS epidemic at a national level are directed and supported by the National Center for the Prevention of STI/HIV/AIDS. The Center has a presence in each province which allows it to distribute advice, broadcast materials, and promote educational programs throughout the country. The center also serves a regulatory role in scientific, technical, and practical matters related to HIV/AIDS both within and outside of the health sector. The organizational and operational structure of the Center reflects its role as national leader in the response to the epidemic.

Notice was taken of the Center’s ability to mobilize, provide technical guidance, respond rapidly and provide material and human resources; the Center assisted the sectors we evaluated to develop educational program and other activities.

The national response to the epidemic was

⁵ Centro de Estudios de Población y Desarrollo. ONE. Encuesta sobre indicadores de prevención de infección por el VIH/sida. Republic de Cuba December 2006

strengthened by access to material and financial resources. This allowed the development of strategic plans, reinforced moral commitments to the program, and heightened the sense of responsibility to protect the health of the Cuban population and carry out the project itself.

Comparing the three provinces evaluated in depth, project management was fairly homogeneous between Holguín and Matanzas provinces, as opposed to Ciudad de la Habana, where the work was noticeably less organized. The following table summarizes the evaluation:

**Overall Evaluation of
By Implementing Agency**
(S: Satisfactory; A: Acceptable)

Agency	La Habana	Matanzas	Holguín
CNP	A	S	S
Radio	S	S	S
Televisión	S	S	S
MTS	S	S	S
MTSS	S	S	S
CESJ	S	S	S
CENESEX	A	S	-
MES	S	S	S
INFOMED	A	S	A

Cross-sector collaboration and the Multisector National Response (MNR)

The MNR project served as a framework guiding the strategic planning and evaluation at each agency. Most of agencies we evaluated had clearly defined strategic plans which were implemented in a wide variety of specific local projects.

The MNR framework encouraged cross-sector collaboration to improve the quality of life of people with HIV; provide comprehensive care; monitor their rights and obligations; foster their non-discriminatory inclusion in work, family, and social circles; and develop community-level educational activities concerning sexual health.

The results of the MNR program were conditioned by the organizational capacity of local coordinators, by their ability to mobilize interest in the project, by the quality of MINSAP program chiefs in each province, and by the operational stability

and effectiveness of local government.

Discrimination and stigmatization

All those we interviewed at the various agencies agreed that discrimination and stigmatization of people with HIV had decreased among workers, students, and the general population. This was seen as resulting from multi-sector action. Mass media clearly played an important role; this underscores the effectiveness of training writers and producers as part of the project.

The ONE survey was consistent the opinions of our interviewees. Persons living with HIV/AIDS report a 20% reduction in feelings of rejection in the past 12 months. 80% reported receiving support from their families and those around them (presumably fellow workers or students). Managers at the Center for the Study of Youth reported less discriminatory responses in young people and teachers in 2005 and 2006; Positive attitudes towards working with people living with HIV were more common, interest in HIV/AIDS was high, and no complaints of discrimination had been received.

Experts felt that ICRT social communicators and producers had played the most important role in combating stigmatization and discrimination of people with HIV. Other key agencies were the Ministry of Education (MINED), MTSS, the Federation of Cuban Women (FMC), and the Ministry of Tourism (MINTUR). The health sector lagged behind in this regard. There have been complaints of HIV/AIDS patients being denied either primary and/or secondary health care; this is particularly the case for dental services. Dentists have a higher risk of infection with HIV and need special training. Persons living with AIDS who received care from the Ambulatory Care System (SAA) reported in the ONE survey that they felt discriminated against by certain hospital doctors and dentists.

Current legislation

Training regarding existing HIV/AIDS legislation had a markedly positive impact on those involved in applying regulations at various levels of the labor and social security system. They face a variety of legal situations related to the disease and found materials on new laws and HIV/AIDS useful in their local work. 96% of the people with HIV interviewed for this evaluation knew that their right to work is enshrined in Cuban law and that they can seek help from management; this could be considered one positive result of the actions of various

social sectors

The ONE survey found that only 25% of those with HIV had received any information concerning laws about HIV/AIDS; however, 98% of those who had gotten information, reported that it was useful. A relatively high proportion those who knew about the Manual on Law and AIDS had actually read it. Practically everyone who read the Manual found it useful which confirms its educational value.

The application of regulations relating to HIV/AIDS and employment is complex. Some people with HIV want to claim disability benefits through the social security system and stop working. They feel they are ill or rely on their family for economic support. Other workers exclude themselves from the workforce because of continued social rejection. In some cases the jobs offered people with HIV/AIDS fall short of their expectations; this can even occur when special considerations—in terms of working conditions and schedules—are made by municipalities. The ONE survey again echoes these findings. Nearly 80% of people with HIV had not consulted an employment office either to seek work, legal advice, or advice on social security. Nevertheless, it is encouraging that most HIV positive people surveyed by ONE were currently either working or studying in the same place where they had been prior to their HIV diagnosis. At least 35% of those who had stopped working or studying in the past year had gone to an employment bureau for assistance. This could be seen as evidence of lessened social stigma, itself the result both of the educational work carried out at the provincial level by those in charge of health and social services as well as the greater knowledge among PLWA's about their disease and their rights.

Shortcomings

- In nearly all cases we could not locate the MNR project plan in any of provinces. Some of the people we interviewed were unaware of the concept. Participation by youth agencies in the MNR was generally felt to be low.

- The health sector as a whole is not clearly recognized in the MNR project plan. This may reflect that a health sector agency—the National Center for Promotion and Prevention of STI/HIV/AIDS—acts a lead agency for the project and oversees cross-sector coordination.

- Ministry of Public Health regulations on the obligations of HIV-positive people and their duty not to act irresponsibly and spread the epidemic are

included in the current penal code. However, in the territories there were contradictory interpretations about how these regulations should be applied. Disagreement exists about who should make a denunciation and how strictly the deliberate transmission of HIV should be dealt with.

- There was consensus among those interviewed—primarily at municipal level—that resources for the project were insufficient. This shortage affected the preparation and preservation of records and project materials. There were cases where there was not enough educational materials to cover distribution needs. Radio stations and TV centers, for instance, suffered serious difficulties in terms of resources; this could jeopardize their ability to carry out activities planned for the next period. This was also the case in municipal employment bureaus and some social work schools.

- Poor management feedback mechanisms were noted at various levels. This meant that information useful for assessing program impact was lacking. The reports sent by provincial and municipal authorities—other than monitoring reports—were not used. Furthermore, copies of these reports and other records of project activities were not always kept at the local level. To cite one example, there is no plan by radio stations to evaluate the impact of their programs although most of them (particularly the provincial stations) have the means to do so. CENESEX is in a position to get information on community impact from their promoters.

- The extensive work undertaken by the project in the labor and social security systems is threatened by the problem of job instability. This could undermine the expected benefits of employee training in legal aspects of this health problem—so fraught with social and moral/ethical concerns—and compromise effective management.

- The impact of CENESEX in terms of project activities was very limited particularly given its national reach, its social mission, and its target population—future physicians and health technicians—a group directly implicated in HIV prevention and the care of people living with HIV. Its involvement in medical schools was limited to five courses on sex education which were offered as an elective. CENESEX did not get involved with the Health Technicians Master’s Program (*Licenciatura*).

- There is still evidence of discrimination in the treatment with people living with HIV in some health services such as medicine and dentistry.

- The National Center for Medical Sciences Information (Infomed) expressed concerns that investment in information technology was not part of the project. InfoMed plays a critical role in ensuring users access to online resources on HIV/AIDS. Among the complaints heard was that in Holguín and Matanzas provinces internet access is restricted to 25 hours a month; this limits access to online resources and the ability to surf the internet. Access to the virtual health library’s digital collections on HIV/AIDS varied in different parts of the country;

Figure 3
Groups impacted by Sector

Groups influenced:	Students	Workers	General Public	At-risk groups
Centro Nacional de Prevención ITS/ VIH/Sida				
Instituto Cubano de Radio y Televisión				
Centro Nacional de Educación Sexual				
Centro de Estudios sobre la Juventud				
Ministerio de Trabajo y Seguridad Social				
Ministerio de Educación Superior				
Cetro Nacional de Información de Ciencias Medicas (INFOMED)				
Direct Influence		Indirect Influence		

sometimes the collections were either missing or incomplete. In the latter case the librarians kept the materials locked up

Final considerations

- During the period under evaluation, this Global Fund project strengthened multi-sector action to prevent and address the HIV/AIDS epidemic at the national level. This was accomplished through the main agencies of central government concerned with the social response to this health issue; they extended their work in society, developed cross-sector collaborations, and worked with MINSAP's National STI/HIV/AIDS Prevention Program.

- Sectors generally fulfilled planned activities and showed progress in terms of organization, planning, systematization, and integration. They were more conscious of their contribution to the prevention and control of the epidemic.

- The development of important local initiatives demonstrated greater autonomy, emotional involvement, and identification with project goals among participants; their work went beyond simply meeting targets. This indicates the potential for sustained action in the future.

- Compared to prior evaluations, multi-sector work had increased remarkably; the quality of management was vastly improved.

- The various agencies and institutions systematically aligned their work with the health sector. Their specialists took part in training courses and workshops, technical advice, and radio and TV programs; this strengthened collaboration among the sectors.

- Interviewees from various sectors agreed that there was less discrimination and stigmatization of people living with HIV, both within their organizations and in the population in general. This was attributed to an increased level of awareness resulting from workers' training and information for the public at large through the mass media. Current legislation addressing HIV/AIDS has helped promote social responses which reject exclusion of people with HIV/AIDS and serve to guarantee their rights and duties.

Recommendations

1. Implement self-assessment within sectors as a means to evaluate outcomes and stimulate feedback.
2. Include the entire health sector as a component of the MNR, not just the National Center for

the Prevention of STI/HIV/AIDS.

3. Ensure that the municipal levels receive both increased material and financial resources, as well as adequate educational materials.
4. Address the remaining discrimination which exists in the health care of people living with HIV in some institutions through specialist training and monitoring/biosafety measures for health care workers.

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