

QUALITY OF LIFE, POSITIVE PREVENTION AND SOCIAL INCLUSION FOR PLHIV PROGRAM

SEMI-ANNUAL REPORT
OCTOBER 2008 – MARCH 2009
COOPERATIVE AGREEMENT: 512-A-00-03-00054-00

Submitted to: The United States Agency for International Development - Brazil
Submitted by: Pact Brasil

APRIL 2009



C O N T E N T S

1. BACKGROUND	3
2. EXECUTIVE SUMMARY	4
3. ACTIVITIES AND RESULTS	5
3.1. PROGRAM OVERSIGHT	5
TECHNICAL, ADMINISTRATIVE AND FINANCIAL MANAGEMENT	5
MONITORING AND EVALUATION	6
3.2. PROGRAMMATIC COMPONENTS	7
HIV/AIDS MONITORING AND EVALUATION SYSTEMS.....	7
DVERSE EVENTS INFORMATION SYSTEM	7
PILOT-PROJECTS IN PARTNERSHIP WITH CSOs.....	8
4. CHALLENGES AND LESSONS LEARNED.....	11
5. SUCCESS STORIES.....	11
6. NEXT STEPS.....	17

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS – Acquired Immune Deficiency Syndrome
APA- Agents of Accession Partners
ARV – Anti-Retroviral
CDC – Centers for Disease Control
CSO – Civil Society Organization
E&S – Employability and Sustainability
FY – Fiscal Year
GIPA- Greater Involvement of People Living with HIV and AIDS
HIV – Human Immunodeficiency Virus
IEC – Informative, Educational and Communication Materials
ITCP - Technology Incubator *Cooperativa Popular*
LAC - Local Advisory Committee
M&E – Monitoring and Evaluation
MER – Monitoring, Evaluation and Reporting
MoH – Ministry of Health
NAP – National AIDS Program
NOTIVISA – National Adverse Events Reporting System
NSC - National Steering Committee
PLHIV – People Living with HIV
RNP+- National Network of People Living with HIV/AIDS
S&D – Stigma and Discrimination
SEBRAE – Brazilian Micro and Small Business Support Service
SENAC – National Service of Commercial Learning
SESI – Industry Social Service
SSO – Strategic Support Objective
TA – Technical Assistance
USAID – United States Agency for International Development
WHO – World Health Organization

1. BACKGROUND

The design and development of the “Quality of Life, Positive Prevention and Social Inclusion for People Living with HIV/AIDS (PLHIV)” Program is linked to the strategic objectives of the United States Agency for International Development (USAID) and the Center for Disease Control (CDC), as well as the priorities and public policies of the Ministry of Health through its National STD/AIDS Program (NAP).

The program’s main objective is to contribute toward improving the quality of life of PLHIV in conditions of social vulnerability in São Paulo, Salvador and Brasilia. Partnerships were formed with civil society organizations (CSO) in these three cities to meet the four strategic objectives of the program:

- To strengthen actions that promote health among PLHIV and positive prevention;
- To promote social inclusion of PLHIV by investing in skills building activities and integrating the private sector and civil society;
- To contribute toward the sustainability and institutional strengthening of CSOs working with PLHIV; and
- To contribute toward the expansion of access to government monitoring and evaluation (M&E) information systems in HIV/AIDS.

In addition to partnerships with CSOs, this program has been effective at integrating the participation of various actors in the development of the program’s goals and activities, in sensitizing strategic local partners, and in its M&E processes. The program has formed a National Steering Committee (NSC) and Local Advisory Committees (LAC) at both the federal and local level with representatives from various entities including, but not limited to: Government, National Network of People Living with HIV and AIDS (RNP+), Positive Citizen Movement, NGO/AIDS Forum, National Business Council in HIV/AIDS and “S” System. Other significant program innovations include specialized technical assistance and continuous monitoring of activities with partner CSOs by stakeholders from both the private and public sector. Additionally, this program has developed a specialized technical, administrative and financial process that replaces the need for formalized sub-agreements with CSO partners.

2. EXECUTIVE SUMMARY

During this period, Pact continued to support three pilot projects in São Paulo, Brasília, and Salvador targeted at increasing the quality of life of PLHIV. Since this program does not support direct sub-agreements with local CSOs, Pact Brasil adjusted administrative and financial procedures that enable support to the programmed activities according to the norms and procedures of USAID and Pact, while not requiring a signed sub-agreement. The pilot projects implemented a number of training activities to build the capacity and skills of PLHIV and increase their employability. To compliment this economic empowerment component, this program features a broad-based strategy to promote improved quality of life through physical activity courses, psychosocial support groups on living successfully with AIDS, and proper nutrition education, recognizing the need of an integrative and holistic approach to health and well-being of PLHIV.

In addition to providing technical and financial oversight to the pilot projects, Pact reviewed the data from the World Health Organization Quality of Life Survey Abbreviated Version

(WHOQOL-ABB). The baseline survey was conducted with PLHIV reached by the pilot projects to monitor the results of the health promotion and quality of life improvement activities implemented through this program. The data was summarized in a report and distributed in December 2008.

Key accomplishments during this period include, but are not limited to, the following activities:

KEY ACCOMPLISHMENTS
<ul style="list-style-type: none"> ▪ Provide financial support to CSOs for specific events related to PLHIV quality of life improvement and network strengthening
<ul style="list-style-type: none"> ▪ Conduct meetings with the Steering Committee and Local Advisory Committees (LAC) to share results and challenges of pilot projects
<ul style="list-style-type: none"> ▪ Conduct meetings with NAP and local tutors to monitor the pilot project and to discuss adjustments for strategies related to young people and positive prevention activities
<ul style="list-style-type: none"> ▪ Provide technical assistance for the implementation of pilot projects activities and M&E
<ul style="list-style-type: none"> ▪ Conduct supervisory visits with NAP representative to pilot projects
<ul style="list-style-type: none"> ▪ Review data and write a report on the baseline WHOQOL survey
<ul style="list-style-type: none"> ▪ Assist pilot projects with the design and content of materials production
<ul style="list-style-type: none"> ▪ Initiate a new purchase of Synovate data

3. ACTIVITIES AND RESULTS

3.1. PROGRAM OVERSIGHT

I. TECHNICAL, ADMINISTRATIVE AND FINANCIAL MANAGEMENT

In FY08, Pact negotiated action plans with each CSO partner implementing a pilot project. During this reporting period, modifications were made to each in-kind agreement to adjust the activities and purchases that Pact will support based on results of the program's first semester. Pact Brasil continued to conduct activities associated with the contracting and monthly remuneration of the local teams (Tutor, project coordinator, facilitators, instructors, consultants, etc.); purchasing materials and equipments for pilot project activities; and the administration of monthly advances to partner institutions intended to cover expenses related to the PLHIV participation at the field activities and trainings.

Pact also continues to provide overall programmatic management support to the pilot projects. Partners are required to submit quarterly reports that detail their activities and any changes to their action plan. Pact reviews and approves these reports before providing additional in-kind support for project activities. In January, Pact and NAP conducted mid-year reviews of the pilot projects. These results led to revised program activities and strategies for the remainder of Year 1.

During this period, Pact also worked with the Tutors to revise the database that contains all of the information related to the pilot projects participants. These revisions are key for accurate program reporting, as well as an integral part of monitoring and follow-up with beneficiaries.

II. MONITORING AND EVALUATION

The program continues to use the MER system developed in coordination with the Steering Committee during Year I. This MER system includes a results framework that guides Pact Brasil and CSOs reporting, with an emphasis on monitoring programmatic achievements, evaluating results, and identifying best practices.

Pact Brasil completed the review of the results from the baseline WHOQOL survey conducted in September and October 2008 to monitor the program's results in terms of quality of life of the benefited PLHIV and measure the following indicators:

- 1) Level of satisfaction with one's quality of life.
- 2) Level of satisfaction with one's health.
- 3) Level of satisfaction with one's current level of energy.
- 4) Level of satisfaction with oneself.
- 5) Level of satisfaction with one's capacity for work.
- 6) Level of satisfaction with the availability of information that one needs.

Quality of life was defined as an "individual's perceptions in the context of their culture and value systems, and their personal goals, standards and concerns" (WHOQOL Group 1994). The results were presented in a baseline report distributed in December 2008. In summary, this study found that 42.1% of PLHIV defined their quality of life as "neither bad nor good," 30.6% as "good", while 3% of the PLHIV considered the quality of life as "very bad". Additionally, 5% of the PLHIV reported that they are "very unsatisfied" with their health, 22.5% reported being "unsatisfied," and 37.5% stated that they were "satisfied." Please see the baseline report for a complete summary of the results and demographic data related to the study population.

Based on these results, the following recommendations for program activities and strategies were made: (i) identify and implement strategies to expand access of the program activities to younger segments of the population; (II) incorporate income generation activities and employability trainings that are geared towards men; (III) implement strategies focused on sensitization of the private sector on the employability of PLHIV; (IV) conduct additional in depth interviews with individual PLHIV and groups to gain a better understanding of their perceptions of quality of life and the influence of stigma and discrimination in their ability to look for work.

While this program was designed to be focused more on the lessons learned from the innovative pilot projects and the qualitative indicators related to an increased quality of life for PLHIV, Pact also collected the following PEPFAR indicators during this reporting period:

PEPFAR INDICATORS
▪ Number of individuals trained in HIV-related institutional capacity building: 15
▪ Number of individuals provided with HIV-related palliative care: 108 (MAPA-50; GAPA-28; GAI-30)
▪ Number of local organizations provided with technical assistance for HIV-related institutional capacity building: 3
▪ Number of local organizations provided with technical assistance for strategic information activities: 3

Additionally, the number of participants in the CSO activities is divided by gender, type of activity, and city as follows:

CSO	City	Activities for PLHIV	Gender	
			Male	Female
MAPA	São Paulo	Training on Positive Prevention	3	9
		Training in Physical and Psychological Balance	9	3
		Training in Nutrition Care	2	9
		Training in Income Generation (handicraft and others)	9	2
GAPA	Salvador	Training in Income Generation (handicraft and others)	7	8
		Training in Income Generation (customization of clothing)	10	2
		Training in Sexual Rights and Reproductive Health, Physical and Psychological Balance	10	17
		Training for Homecare Educators (APA)	6	17
		Training in interpersonal and work relationships	6	17
GAI	Brasilia	Training in Income Generation (sewing course)	2	8
		Training in Income Generation (executive waiter course)	3	5
		Training in Nutrition Care	13	17
		Training in Physical and Psychological Balance	11	18
		Training in Income Generation (pieces of costume jewellery)	2	5
		Training in Income Generation (customization of clothing)	5	3

3.2. PROGRAMMATIC COMPONENTS

I. HIV/AIDS MONITORING AND EVALUATION SYSTEMS

This program component is related to the program's Strategic Objective 4 and is linked to the technical-operational support provided to NAP for acquisition of the Synovate. To date, Pact has already procured the 2002, 2003, 2004, 2006, and 2007 date sets, allowing NAP to aggregate this data with other data generated by different information systems of the Ministry of Health (MONITORAIDS), thus producing analyses on HAART and the definition of therapeutic consensus and/or public policies for treatment and care of HIV/AIDS.

During the period reported, Pact Brasil had discussions with NAP and Synovate regarding the provision of additional data set. Thus during the next reporting period Pact Brasil will finalize a contract with Synovate and will procure the 2008 database.

II. ADVERSE EVENTS INFORMATION SYSTEM

This component was related to the program's Strategic Objective 4 and linked to the technical-operational support provided by Pact Brasil to NAP for implementation of the notification system of adverse event and technical complaint (NOTIVISA) on products and services for HIV/AIDS treatment.

During FY08 Pact Brasil discussed with NAP team a range of strategies to move forward on NOTIVISA activities. It is important to note that the implementation of this information system involves a strong partnership between NAP and the National Surveillance Agency (ANVISA) to put together all data and systems related to HIV/AIDS treatment, allowing health professional and PLHIV from all country to providing information about the effects of HIV/AIDS medicines. NAP and ANVISA have faced great difficulties and delays to finalize the necessary arrangements for NOTIVISA information system. Due that, in February, USAID, Pact Brasil and NAP decided to eliminate this component from the program, agreeing that the funds allocated for this component should be re-budgeted for work with young people as part of NAP's new PLHIV strategy.

III. PILOT-PROJECTS IN PARTNERSHIP WITH CSOs¹

All the three pilots projects seeks to improve the quality of life for PLHIV by providing prevention activities focused on positive prevention; conducting anti-retroviral (ARV) treatment adherence and nutrition counseling; facilitating group therapy sessions; advocating for increase human rights for PLHIV; and providing professional skills development trainings related to income generating activities.

During the reported period the pilots projects moved forward on the activities implementation defined on July 2008, associated with the themes described below. Pact Brasil team and the Tutors accompanying all activities developed by the pilot projects providing technical support also to overcome the difficulties faced by the CSOs teams.

Approximately US\$ 145,000 was invested in the three pilot projects² to cover the costs of the team, inputs and equipment, transport and feeding of participants (PLHIV), Tutor remuneration and specialized consultancy in the area of Employability & Sustainability (E&S).

On January 2009 Pact Brasil and NAP conducted mid-year reviews of the pilot projects, considering their seven months of activities implementation (July 2008 – January 2009). The results of this review indicated a range of needs in terms to realign the pilot projects strategies, being the most important of them the necessity to increase the number of PLHIV reached in each city. Therefore the pilot projects and Tutors received from Pact Brasil and NAP technical instructions and political support to launch partnerships with public health services allowing the implementation of CSOs activities at key HIV/AIDS units where is possible to access and involve a bigger number of PLHIV (including young people) in positive prevention, treatment adherence and income generation strategies.

To complement this process Pact Brasil and NAP conducted technical supervisory visits to the pilot projects during February and March 2009, to observe the field activities, to reinforce aspects of the incorporation of new strategies for the next months, and to participate at the Local Advisory Committee meetings.

Key achievements related to each pilot project during this period include, but are not limited to, the following summarized information.

¹ Photos of the Program activities from the CSOs have a restricted circulation, and **should not be disseminated outside of this report**. There is no formal signed consent for use of these images, as the photos were sent to Pact Brasil from our partner CSOs. Here they are used only to illustrate this report, trusting this report's readers to protect the confidentiality of the activity participants.

² US\$ 66,380 GAI – US\$ 38,095 GAPA – US\$ 39,890 MAPA.

“EXTENSÃO DAS OFICINAS DE CONVIVÊNCIA - MAPA”

Summary of Activities:

Through MAPA’s partnerships, PLHIV have been able to register, market and distribute the items they produce during a number of income generating activities through the Office of the Arts Bazaar. This greatly increases the potential market for their goods.

In December 2008 and March 2009, a strategy that focuses on increasing the number of young people participating in this pilot project was developed. Events focused on coexistence among young people (between them and their families) were held to broaden and diversify the age profile of the PLHIV reached by the pilot project. A total of 32 young people ages 11-20 years old participated on each event.



MAPA conducted a number of Nutrition Workshops that received very positive feedback from the participants. These workshops covered a range of topics including, but not limited to: how to prepare new foods, cleaning/purifying foods, how to strengthen one’s immune system, and a review of how the intestinal/digestive system functions.



The workshop on Positive Prevention attracted a number of new beneficiaries to the pilot project, and created opportunities for PLHIV to have extensive dialogue on a number of issues related to prevention and stigma and discrimination, as well as develop new relationship of mutual support and understanding with their peers.

The Office of Physical Balance, at the headquarters of the OSC, has continued to provide opportunities for physical activity for the PLHIV who participate in this pilot project. Activities include: relaxation, localized exercises, aerobic dancing, walking, and Tai Chi.

MAPA has seen technical improvements in the production of crafts following the Crafts Workshops. Additional workshops on Marketing compliment the Crafts workshops by building the capacity of PLHIV to successful market their products, and ultimately improve their earning potential.

“EMANCIPAÇÃO E ADESAO” - GAPA/BAHIA

Summary of Activities:

In order to address the demands made by the participants to develop a business cooperative, a partnership was established with the Brazilian Micro and Small Business Support Service (SEBRAE) and Technology Incubator *Cooperativa Popular* (ITCP) allowing two meetings with PLHIV about cooperatives and one meeting on professional etiquette.



Ten PLHIV were selected from the pilot project to receive training to act as Agents of Adherence Partners (APA). The responsibilities of APA include hospital and home support to PLHIV and facilitating workshops at public health services related to HIV/AIDS. APA were trained on issues related to ARV adherence, home visits, and psychosocial support.

Following the painting workshops in the previous reporting period, there was a great demand for a follow-up art workshop. Pilot project participants identified ceramics as a potential having potential to marketed broadly, and a thus a ceramics workshop was held in December 2008.

Additional 'Customization of Clothing' workshops were held in October through December for participants to refine their skills in painting t-shirts. During these workshops, participants also discussed the possibility of forming a cooperative to make the production and marketing of their products competitive against larger, more established businesses.



In November, a partnership established with Swasthya Yoga allowed PLHIV participants of the pilot project to participate in yoga classes administered by professionals yoga instructors for free.

In order to meet the principles and directives of GIPA, this pilot project reinforces the integration of PLHIV as executors of the activities and not only as beneficiaries. Several PLHIV are performing key functions in workshops and other activities of this pilot project.

"INCLUSÃO POSITHIVA – GRUPO ARCO IRIS"

Summary of Activities:

As part of the communication strategy for the program, Pact Brasil supported the creation of the Arco-Íris website (<http://www.grupoarcoiris.org.br>) to increase also the visibility of the pilot project activities.



Two professional courses – Waitressing and Alterations/Sewing – were conducted in partnership with the Educational Center for Professionals, an institution dedicated to continuing adult education program that provide participants with certifications of qualification. Eighteen PLHIV participated in these trainings from the pilot projects.

In partnership with local University, NAP, USAID and Pact Brasil, GAI has promoted on November 2008 the first Lipodystrophy Seminar, with approximately 70 participants. During the Seminar was possible to discuss with health professionals and governmental representatives issues and solutions to face this ARVs side effect.



Food and nutrition activities were performed during the monthly socialization meetings that focused on preparing healthy food to support their ARV adherence. Other issues discussed as these monthly meetings included hygiene, safe packaging of food products, and freezing of food items from home gardens for use throughout the year.

Alterations and sewing is a highly informal business in Brazil, creating additional logistic problems for continuing this type of work. To overcome this challenge and promote the generation of income, GAI allows PLHIV to use its office space and equipment during the week to work on altering clothes and sewing for the orders they are able to generate.

GAI developed and applied a Nutritional Assessment and Monitoring Sheet that monitors individual's physical condition, including the effects of lipodystrophy, and outlines possible nutrition and physical conditioning strategies to address a variety of issues and concerns.



As part of the physical conditioning activities, GAI developed an informational brochure for PLHIV that contains medical information concerning the limitations for physical activity that PLHIV should observe for healthy living and to adhere to their treatment.

4. CHALLENGES AND LESSONS LEARNED

As the pilot projects near the end of their first full year of implementation, they continue to experience a number of environmental challenges that impact the reach of their program activities. PLHIV continue to experience a high level of stigma and discrimination in both the formal job market and among their family and friends. The PLHIV in the areas in which the CSOs work are extremely poor and while they desire the benefits they would gain from participating in program activities, many are hesitant to take part in the CSO's trainings and activities because they fear the stigma of being associated with an HIV/AIDS program. CSOs are trying to find new strategies for interacting with PLHIV to address this challenge. Because the majority of PLHIV attend their local public health centers to receive treatment and meet with their doctors, CSOs are considering using these centers as a target location for positive prevention program activities.

Continued stigma and discrimination has also made it difficult for Pact Brasil to engage the private sector in program activities. Most private sector companies want to publicize any contributions they make to community programs, but PLHIV do not want to be identified in photographs and other means of publicity. Additionally, the global economic crisis has limited the funds that private companies are putting towards corporate social responsibility activities.

In addition to lipodystrophy, PLHIV also have other serious consequences related to appearance and physical conditioning resulting from the use of HAART. Despite the fact that such issues are already part of the public health agenda of the government, the activities of the CSOs must provide alternative resources for PLHIV. While many of these environment challenges cannot be controlled, together Pact and the pilot programs are developing new strategies to address them and continue to expand this program's outreach to PLHIV.

5. SUCCESS STORIES

JOBS PROJECT TRAINS BRAZILIANS WITH HIV/AIDS

Eliana initially hesitated to look for employment, discouraged by her low-level of education and limited professional experience. "I didn't even have the courage to start searching for a job", she comments. Living with AIDS for four years, she was tired of depending on government allowances to sustain her son and husband, who are also HIV positive.



Eliana now forms part of the first group of ten beneficiaries improving their professional skills and employability through training support from Arco-Iris, an HIV/AIDS NGO located in Brasília and one of three Pact supported pilot projects. Eliana and her fellow participants have been trained in proper food service and hospitality techniques. Most of the participants have already secured jobs at various events and local restaurants. "This workshop has made a big difference for me in terms of opening doors to the job market," Eliana notes.

Sandra, another beneficiary, has continued improving her professional skills after completing the course. She is now enrolled in a two-month course geared toward employment as a server in the restaurant sector. "I see this as an opportunity to find a regular job in the future and stop my diagnosis from limiting me," she adds.

According to Arco-Iris Vice President Antonio Lisboa, this project fulfills a long-standing need of PLHIV for professional qualification and income generation. "These people have never had an opportunity to improve their job skills mainly due to their HIV/AIDS diagnosis. For them, having the chance to work again also means an improvement in many other dimensions of their lives, such as their health, educational levels, civic participation and social life." To bolster job placement of graduated trainees, the program also plans to develop databases of job opportunities in the community and establish a professional center with comprehensive job-related programming.

ARISLENE – AN ENTREPRENEUR OF FASHION

Depression was Arislene's first side effect from HIV. She was at a crossroad in her life after having just ended a serious four year dating relationship and then finding out she was HIV positive. She was 21 years old, and although her life was only just beginning, she felt like it was ending.

Arislene worked at the headquarters of a carnival block, where she suffered much discrimination because of the symptoms of her disease. People suspected that she was HIV positive, and were very aggressive towards her. She was also having difficulties at home with her mother and step-father, causing her depression to become more severe. With the help of a few supportive friends, she was able to move out of her parent's house and live alone for the first time.

Arislene has the characteristics of a good entrepreneurial: she is always in search of new innovations; she appreciates quality products; and she has the gift of a natural saleswoman. To occupy her time and produce some income, Arislene began making jewelry. At first, she copied other jewelry pieces and then reproduced similar products. Then, she began experimenting on her own with the design of new products.



Shortly after her business began, Arislene was introduced to a GAPA/BAHIA Living + group where she was able to participate in courses on art and entrepreneurship. There she learned that she could expand her production and sell her products in boutiques for clothes and fashion accessories. Today, Arislene serves a network of customers and supplies a shop in a prime district of Salvador with beautiful hand-made jewelry.

Arislene estimates that every month she earns more than one and a half times the minimum wage in Brazil. She reinvests her profits in materials to ensure product quality and new courses to improve

her skills, as she learned in one of her first business trainings through the pilot project in Salvador. Through this project she has also had the opportunity to meet other women who also produce jewelry and exchange experiences and partner with them to increase their line of production. After designing a new product, Arislene is able to task the production of the new pieces to other PLHIV women in her "co – producing" group, and Arislene is able to devote more time to sales.

Today, five years after learning her HIV status, she is a businesswoman. Arislene is evaluating the possibility of accessing a micro-credit loan to expand her business and her opportunities. Along with nine other PLHIV, she has formed a new Living + group associated with GAPA/BAHIA that also assists and supports PLHIV in their homes or at the hospital. Arislene loves life her life today, and believes that with courage and optimism she can overcome any obstacle.

6. NEXT STEPS

This program's current end date is September 2009. In March 2009, Pact Brasil also submitted a one year no-cost extension request to USAID/BRAZIL in order to:

- Support the Brazilian Ministry of Health's National AIDS Program (NAP) to implement a strategy directed at young people living with HIV and AIDS in all Brazilian states; and
- Extend the life of project of current pilot programs implemented in partnership with local NGOs and directed at people living with HIV and AIDS in three Brazilian cities.

A timely response to this request is necessary in order to plan the remainder of activities for this fiscal year. Based on the assumption that Pact will receive a positive response to the no-cost extension request, Pact Brasil will focus on the following key activities during the next reporting period:

KEY ACTIVITIES FOR APRIL-SEPTEMBER 2009
▪ Intensify the development of activities related to income generation, social inclusion and professional skills improvement
▪ Promote and stimulate business participation in activities and policies against stigma and discrimination
▪ Procure Synovate database (2008 data)
▪ Facilitate, review and approve new Year 2 work plans for the pilot projects
▪ In coordination with the Steering Committee, design and implement new strategies for the pilot projects after June 2009 (Year 2)
▪ Conduct an evaluation workshop with pilot projects, Local and National Committees representatives
▪ Conduct evaluations of the pilot projects with NAP and USAID at the end of Year 1 of CSOs activities
▪ Provide technical support to the pilot projects in the implementation of field activities and M&E
▪ Support NAP initiative to form new youth people living with HIV/AIDS internship program

PROGRAM CONTACTS

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