

# Reinforcing civil society contributions to health

A publication in the German Health Practice Collection



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To Fight AIDS, Tuberculosis and Malaria

  
**ICASO**  
INTERNATIONAL COUNCIL OF  
AIDS SERVICE ORGANIZATIONS

## Acronyms and Abbreviations

AfriCASO	African Council of AIDS Services Organizations	GNP+	Global Network of People Living with HIV/AIDS
amfAR	American Foundation for AIDS Research	GPA	Global Programme on AIDS
BACKUP	German BACKUP Initiative (Building Alliances, Creating Knowledge and Updating Partners)	GTZ	Deutsche Gesellschaft für Technische Zusammenarbeit GmbH (now GIZ)
BMZ	Germany's Federal Ministry for Economic Cooperation and Development	HDI	Human Development Index
BSS	Behavioural surveillance survey	ICAD	International Coalition on AIDS and Development
BURCASO	Burkina Council of AIDS Service Organizations/ Conseil burkinabé des ONG, OBC et associations de lutte contre les IST/VIH-Sida	ICASO	International Council of AIDS Service Organizations
CCM	Country Coordinating Mechanism	IEC	Information, education and communications
CCSS-JHU	Center for Civil Societies Studies at Johns Hopkins University	IPPF	International Planned Parenthood Association
CDC	Centers for Disease Control, United States	LGBTs	Lesbian, gay, bisexual, and transgender people
CeSaJo	Centro Salud Joven (Youth Health Centre), Santo Domingo	MARPs	Most at risk populations
CoATS	Coordination of AIDS Technical Support	M&E	Monitoring and Evaluation
COIN	Center for Integrated Training and Research (El Centro de Orientación e Investigación Integral)	MSM	Men who have sex with men
COTRAVEDT	Comunidad de Trans Trabajadoras Sexuales Dominicanas	OVPs	Other vulnerable populations
COPRESIDA	Consejo Presidencial del SIDA (Presidential AIDS Council), Dominican Republic	PAHO	Pan American Health Organization
CSAT	Civil Society Action Team	PAMAC	Support Programme for Community Associations
CSO	Civil Society Organization	PANCAP	Pan Caribbean Partnership against AIDS
CTAG	Caribbean Treatment Action Group	PEPFAR	President's Emergency Plan for AIDS Relief
CVC	Caribbean Vulnerable Communities Coalition	PR	Principal Recipient
DHS	Demographic and Health Survey	ProSuRe	GTZ Supra-regional Project "Youth and AIDS in the Caribbean"
DIGECITTS	Dirección General de Control de Infecciones de Transmisión Sexual y VIH/SIDA (Division for Controlling STIs and HIV)	RNJ	Red Nacional de Jóvenes (National Youth Network)
EU	European Union	SR	Sub-Recipient
GASCODE	Groupe d'appui en santé, communication et développement	SSR	Sub-sub Recipient
GDC	German Development Cooperation	STI	Sexually Transmitted Infection
GHPC	German Health Practice Collection	UNAIDS	Joint United Nations Programme on HIV/AIDS
GIST	Global Implementation Support Team	URCB/SIDA	Union of Religious and Customary Burkinabe against AIDS
GIZ	Deutsche Gesellschaft für Internationale Zusammenarbeit GmbH	YurWorld	Youth in the Real World

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A BACKUP approach to making Global Fund money work

Acknowledgements	4
The German Health Practice Collection	5
Executive Summary	6
Civil society, ICASO and the Global Fund	8
The German BACKUP Initiative: Supporting the Global Fund's work with many partners	11
Case 1: The Civil Society Action Team	13
Case 2: Burkina Council of AIDS Services Organizations and its contributions to Burkina Faso's response to TB	16
Case 3: Youth in the Real World and its contributions to the Dominican Republic and Caribbean responses to HIV	21
Lessons learnt from CSAT, BURCASO and YurWorld	26
Peer Review	27
References	29

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# German Health Practice Collection

## Objective

In 2004, experts working for German Development Cooperation (GDC)<sup>1</sup> and its international and country-level partners around the world launched the German HIV Practice Collection and, in 2010, expanded it into the German Health Practice Collection (GHPC). From the start, the objective has been to share good practices and lessons learnt from BMZ-supported initiatives in health and social protection. The process of defining good practice, documenting it and learning from its peer review is as important as the resulting publications.

## Process

Managers of GDC-supported initiatives propose promising ones to the Managing Editor of the GHPC at [ghpc@giz.de](mailto:ghpc@giz.de). An editorial board of health experts representing GDC organizations at their head offices and in partner countries select those they deem most worthy of write-up for publication. Professional writers then visit selected programme or project sites and work closely with the national, local and GDC partners primarily responsible for developing and implementing the programmes or projects. Independent, international peer-reviewers with relevant expertise then assess whether the documented approach represents 'good or promising practice', based on eight criteria:

- Effectiveness
- Transferability
- Participatory and empowering approach
- Gender awareness
- Quality of monitoring and evaluation
- Innovation
- Comparative cost-effectiveness
- Sustainability

Only approaches meeting most of the criteria are approved for publication.

## Publications

All publications in the GHPC describe approaches in enough detail to allow for their replication or adaptation in different contexts. Written in plain language, they aim to appeal to a wide range of readers and not only specialists. They direct readers to more detailed and technical resources, including tools for practitioners. Available in full long versions and summarized short versions, they can be read online, downloaded or ordered in hard copy.

## Get involved

Do you know of promising practices? If so, we are always keen to hear from colleagues who are responding to challenges in the fields of health and social protection. You can go to our website to find, rate and comment on all of our existing publications, and also to learn about future publications now being proposed or in process of write-up and peer review. Our website can be found at [www.german-practice-collection.org](http://www.german-practice-collection.org). For more information, please contact the Managing Editor at [ghpc@giz.de](mailto:ghpc@giz.de).

<sup>1</sup> GDC includes the Federal Ministry for Economic Cooperation and Development (BMZ) and its implementing organizations Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH and KfW Entwicklungsbank (KfW).

## Executive Summary

In many countries, faith-based and other civil society organizations (CSOs) were pioneers in providing the health services we now consider essential. Now governments are often well placed to provide core health services but – as the global AIDS epidemic has served to remind us – CSOs continue to play important roles in ensuring that those services are extended to poor and otherwise marginalized and vulnerable populations.

In 1991, the International Council of AIDS Service Organizations (ICASO) became the first international organization dedicated to promoting and supporting the participation of CSOs in the response to AIDS at the global, regional, national and local levels. They were soon joined by others and, together, such organizations played key roles in the conception and 1996 birth of the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the conception and 2002 birth of the Global Fund to Fight AIDS, Tuberculosis and Malaria. UNAIDS and the Global Fund are both committed to “multisectoral responses to disease” – with public, private and civil society partners collaborating on coordinated responses.

Also born in 2002, the German BACKUP Initiative was designed to provide technical support to partners as they build their capacities to qualify for Global Fund financing and then put that financing to effective use. After discussing all of the foregoing in greater detail, this publication focuses on three examples illustrating BACKUP’s demand-driven and flexible approach to supporting civil society capacity-building in particular.

The first example looks at an ICASO initiative launched in 2008 and known as the Civil Society Action Team (CSAT). With seven Regional Hubs, CSAT aims to help CSOs identify and overcome their capacity-building challenges so they do not miss opportunities to reap optimal benefits from Global Fund financing. The second example looks at the Burkina Council of AIDS Services Organizations (BURCASO) and focuses on the challenges it faces, in a severely resource-limited setting, as it participates in a Global Fund Round 8 tuberculosis project. The third example looks at the Youth in the Real World (YurWorld) project in Dominican Republic. It addresses HIV among marginalized youth, serves as a model for the whole Caribbean region, and now oversees the Marginalized Youth sub-component of the Vulnerabilized Groups component of a regional Global Fund Round 9 HIV/AIDS project.

Lessons drawn from these examples include:

- Community-based CSOs established by members of marginalized and vulnerable populations are often best placed to provide those populations with services, but they need support to do this effectively.
- Support must be flexible and timely, responding to challenges and opportunities as they emerge.
- CSOs are eager and well able to benefit from the type of capacity-building support that BACKUP offers.
- Staying the course pays off in the long run. There is value in continued interest in effective CSOs and their programmes and, when the moment is right, in providing them with additional support even when earlier support was not entirely successful.
- Support for CSOs often has knock-on benefits, since they are often multi-functional and building their capacity to perform one function often builds their capacity to perform others.
- During times of cut-backs in development aid, CSOs that can legitimately claim to represent and serve the poor and the otherwise marginalized and vulnerable should not be pushed to the back of the line.

Two independent peer reviewers have assessed the BACKUP approach and found it to be “at the cutting edge” of providing technical support to CSOs that benefit or hope to benefit from Global Fund financing and cite, for example, its efforts to support CSOs representing and serving marginalized groups in countries and regions with weak human rights legislation and enforcement.



## Outline of this publication

This publication is divided into seven sections. The first summarizes the pioneering and continuing role civil society organizations (CSOs) play in health systems, how the AIDS epidemic shone a light on that role, how the International Council of AIDS Service Organizations (ICASO) and Global Fund to Fight AIDS, Tuberculosis and Malaria came into being, and what those entities do to support CSOs.

The second section describes the German BACKUP Initiative and how it provides technical assistance to CSOs as they build their capacity to qualify for Global Fund financing and put that financing to effective use.

The third, fourth and fifth sections present three examples that illustrate the diverse and flexible nature of BACKUP's support for CSOs, the challenges that CSOs face and what they are sometimes able to achieve even in the face of daunting challenges.

The sixth section draws lessons from the three examples and the seventh and final section provides two independent peer reviewer assessments of the BACKUP Initiative, based on the information provided in this publication.

# Civil society, ICASO and the Global Fund

## Civil society's role in providing essential services

In many countries, faith-based and other CSOs were providing education, health, social and other services that are now seen to be essential long before governments were doing so. Today, they often partner with governments in providing those services and, when governments cut back, CSOs are left trying to fill the gaps.

Governments are often best able to provide core services but CSOs are often best able to ensure those services are extended to the poor, illiterate, marginalized, and otherwise vulnerable – not least, women and youth. They often do this by advocating for human rights legislation and enforcement and by providing information, education and communications (IEC) that help create the social and political environments where everyone's rights to essential services are recognized and respected. They also do it by providing supplementary services that, for example, target specific populations with services specific to their needs.

CSOs are often very strongly committed. Even when they have no resources but their own volunteer labour and even when they are opposed by the media, general public, faith-based leaders, and politicians, they forge ahead and sustain their efforts on behalf of the people they represent and serve. While governments and various faith-based and other CSOs often oppose each other, the resulting debate often leads to compromise and new or improved services to previously neglected and marginalized minorities.

Among the challenges CSOs present to their potential partners is that they are usually not well-regulated by government. In many countries, anyone can establish a CSO that claims to represent a certain population or to provide certain services. It is always prudent to ask for evidence supporting these claims and, also, to ask whether or not there might be other CSOs making similar claims and, perhaps, equally or better able to support them with evidence. It is also prudent to look for possible weaknesses in even the most legitimate of CSOs and to identify any needs they may have for capacity building.

## How the AIDS epidemic shone a spotlight on civil society

The AIDS epidemic first came to the attention of medical science in 1981, when gay men in North America and Europe began presenting with unusual combinations of symptoms and rare diseases. While medical institutions and public health systems focused on clinical responses to the illness and its symptoms, existing and newly formed CSOs drove swift and vigorous response to AIDS among gay men. They did the same among transgender people, sex workers and drug users as it became evident that they, too, were most-at-risk-populations (MARPs) – i.e., far more likely to be diagnosed with AIDS than were most other people. These CSOs focussed on providing: public education and advocacy, prevention and early diagnosis among MARPs, and health and social care for people living with HIV.

### Box 1. What are “civil society organizations”?

In 2004, the Center for Civil Society Studies at Johns Hopkins University (CCSS-JHU) hosted a conference in Nairobi, Kenya, that defined “civil society organizations (CSOs)” as:

Any organisations, whether formal or informal, that are not part of the apparatus of government, that do not distribute profits to their directors or operators, that are self-governing, and in which participation is a matter of free choice. Both member-serving and public-serving organisations are included. Embraced within this definition, therefore, are private, not-for-profit health providers, schools, advocacy groups, social service agencies, anti-poverty groups, development agencies, professional associations, community-based organisations, unions, religious bodies, recreation organisations, cultural institutions, and many more (CCSS-JHU, 2004).

The conference agreed that political parties may seem to fit within this definition but, for practical purposes, should be excluded.



As the AIDS epidemic surfaced in other parts of the world, particularly in low- and middle-income countries with few resources, different types of populations came to be affected. In North America and Europe, HIV continued to be confined to a few MARPs and those living with HIV were predominantly male. In many other countries, HIV spread into the general population and more than half of all people living with HIV were women. Young women, in particular, were particularly vulnerable to HIV infection for physiological, sociological and behavioural reasons.

As the shape of the epidemic changed, so did the makeup of the CSOs that sprang up in response. In some African countries, for example, they were made up largely of parents and relatives of people living with HIV but they were also made up of employers, employees and trade unions concerned about particularly vulnerable workers. Whatever their membership these CSOs were often small and community-based and, whether or not they were connected through national or international networks, they often responded to the epidemic with much greater speed and efficacy than did public health authorities. At the same time, their efficacy usually depended on their ability to establish good working relations with those authorities or, at least, with the hospitals and health centres under their jurisdiction.

### The International Council of AIDS Service Organizations

The World Health Organization established its Global Programme on AIDS (GPA) in 1987 amidst growing recognition that AIDS was not just a health issue but a human rights issue because its main modes of transmission were surrounded by secrecy, embarrassment, taboo, and legal prohibition and punishment. It was increasingly apparent that CSOs had important roles to play in responding to this situation and so, in early 1989, GPA hosted the world's first international meeting of CSOs concerned with AIDS.

Discussions that began at the 1989 meeting eventually gave birth to the International Council of AIDS Service Organizations (ICASO) at the Seventh International AIDS Conference in Florence in 1991. Since then, ICASO has been a member of the IAC's Conference Coordinating Committee and has played a prominent role in ensuring civil society participation in each new IAC and in other international forums.

Until recently, ICASO had five regional secretariats representing and serving community-based CSOs in more than 100 countries but, in February 2012, two of these announced their separation from ICASO. Whatever may be ICASO's future, it has never aspired to be the only international organization representing and serving CSOs involved in the response to HIV. Since ICASO's birth in 1991, other AIDS-specific international organizations have been born. In 1993, for example, the Global Network of People Living with HIV/AIDS (GNP+) and the International HIV/AIDS Alliance were established.

### The Global Fund to Fight AIDS, Tuberculosis and Malaria

ICASO, GNP+ and the International HIV/AIDS Alliance and other international CSOs were prominent in the discussions that gave birth to the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 1996. Replacing the WHO's GPA, UNAIDS was defined by its commitment to joint multisectoral responses to AIDS whereby public, private and civil society partners collaborate in coordinated responses to AIDS at global, regional, national and local levels.

ICASO, GNP+ and the International HIV/AIDS Alliance were also prominent in discussions that led to the UN General Assembly's Millennium Declaration (United Nations, 2000) and Declaration of Commitment on HIV/AIDS (United Nations, 2001). Those declarations gave rise to the Global Fund to Fight AIDS, Tuberculosis and Malaria, launched in January 2002. The involvement of civil society in all aspects of its governance and work is one of the founding principles of the Global Fund. Its Framework Document states that it "will support programs that stimulate partnerships involving government and civil society" and "focus on the creation, development and expansion of government/private/NGO partnerships". Like UNAIDS, the Global Fund is committed to multisectoral responses to disease and this is made manifest in its Country Coordinating Mechanisms (CCMs). In many countries, CCMs are the entry points for civil society participation in planning and implementation of national responses to disease.

Recognizing the uncertainty of longer term financing to support community action for health, the Global Fund now encourages applicants to include measures to strengthen community systems in their proposals for new or continued funding. To provide them with guidance, it has developed a Community Systems Strengthening (CSS) Framework

**Box 2. The Global Fund's achievements over its first ten years**

Over the ten years between its launch in January 2002 and the end of 2011, the Global Fund to Fight AIDS, Tuberculosis and Malaria approved grants totalling US\$22.6 billion to support 1,000 programmes in 150 countries. Of the total amount, 57 percent went to support AIDS programmes, 14 percent to support TB programmes and 29 percent to support malaria programmes. As a result, an estimated 3.3 million people have received antiretroviral therapy, an estimated 8.6 million people have received treatment for TB and an estimated 220 million insecticide-treated mosquito nets have been distributed to prevent malaria (Global Fund, 2011c).

A Results Report 2011 found that, by the end of 2009, the money had been allocated as follows:

- 36 percent to ministries of health and 15 percent to other government organizations;
- 3 percent to faith-based organizations and 33 percent to other CSOs and academia;
- 7 percent to the UNDP and 4 percent to other multilateral organizations;
- 2 percent to private sector organizations (Global Fund, 2011a).

showing the kinds of measures they may wish to include in their proposals. This is just one example of how the Global Fund's policies and mechanisms for strengthening civil society participation continue to evolve over time. Another example is that the Global Fund now promotes and supports dual-track financing whereby CCMs nominate PRs from both government and civil society.

### Global Fund analysis: CSOs top its performance rankings

In April 2011, the Global Fund published an analysis comparing the performance of all of its grants from 2005 to 2010 by category of Principal Recipient (PR): civil society, government, private, and multilateral/bilateral organization (Global Fund, 2011). Table 1 looks at the performance of Global Fund grants given to each category of PR and breaks civil society

down into three sub-categories: international, affiliated with international, local. It shows that, from 2005 through 2010, grants to civil society outperformed those to all others, as measured by whether they met or exceeded expectations. The analysis should be treated with caution, since different criteria were used for different categories of PR so the performance ratings are not strictly comparable. Moreover, the analysis only looks at performance by PRs and not by Sub-Recipients (SRs) or Sub-sub-Recipients (SSRs). Nonetheless, it suggests that, on average, grants to CSOs significantly outperform grants to government, private and multi/bilateral organizations. While more data and analysis would be necessary to come to any conclusions, the particularly strong performance of affiliated CSOs may suggest that local CSOs supported by international networks of CSOs may have certain advantages. However, the significant year-over-year improvement of unaffiliated local CSOs may suggest that they are catching up with the support they have been getting for capacity-building.

**Table 1. Percentage of Global Fund grants meeting or exceeding expectations, 2005-2010**

Principal Recipient	2005	2006	2007	2008	2009	2010
Civil society (total)	27.8	22.8	40.0	54.7	53.0	52.0
- International	41.7	37.3	50.0	47.8	50.9	50.0
- Affiliated with International	n/a	10.0	57.1	58.8	80.0	90.9
- Local	0.0	9.3	27.4	52.3	51.5	48.2
Government	11.5	21.0	32.7	45.2	38.7	31.0
Private	0.0	3.8	23.3	41.7	27.3	40.0
Multi/bilateral	16.7	10.9	25.5	32.3	41.2	36.7

>> Source: Global Fund, 2011b

# The German BACKUP Initiative: Supporting the Global Fund's work with many partners

## BACKUP's mission

Those participating in the discussions leading to launch of the Global Fund recognized that partners in the public, private and civil society sectors would need technical support to participate in Global Fund processes. GTZ (one of GIZ's three predecessors)<sup>2</sup> launched the German BACKUP Initiative in 2002 in order to provide such support in a manner consistent with Germany's policies on HIV, health, human rights, and health systems strengthening.<sup>3</sup> (Frequently updated, the current policies are outlined in BMZ, 2007, 2009a and 2009b.)

In summary, BACKUP offers public, private and civil society partners technical support, first, to access Global Fund financing with sound proposals and, second, to make effective use of any grants that result from those proposals. BACKUP aims, in particular, to:

- Develop the capacities of partner organizations to act as PRs, SRs and SSRs and to manage Global Fund grants and related programmes and projects efficiently and effectively;
- Increase effective participation of civil society in all Global Fund processes;
- Integrate programmes responding to HIV, tuberculosis and malaria into countries' health systems;
- Develop and scale-up gender-sensitive responses into programmes financed by global health initiatives.

Since its inception in 2002, the BACKUP Initiative has supported over 430 capacity-building interventions in 65 countries.

## How it works

BACKUP is largely demand driven and considers requests from any of the partners engaged in Global Fund processes at international, regional and national levels. Requests often come to BACKUP through referral from GIZ's country offices, from multilateral organizations (e.g., UNAIDS, WHO) or from international CSOs such as ICASO and the International Planned Parenthood Federation (IPPF) on behalf of their country-based member organizations. In addition, BACKUP

partners with other organizations on providing or brokering technical support directly to country-based organizations, including CSOs.

The services provided are diverse and include the provision of short and long-term seconded staff, financing for consultants with relevant expertise, and subsidies for activities such as network building, national advocacy and communications. BACKUP supports UNAIDS and WHO in fulfilling their mandates to develop international HIV guidelines and training curricula; to adapt and put them to use in partner countries; to promote and support HIV prevention, universal access to treatment, gender equality, the linking of HIV to sexual and reproductive health, and HIV knowledge management. To these ends, BACKUP plays an active role in international efforts to coordinate technical support and, working with the WHO, it supports the work of five regional HIV Knowledge Hubs in sub-Saharan Africa, Eastern Europe and Central Asia.

## How BACKUP's resources have been allocated

In the five years period between 2007 and 2011, BACKUP has expended a total of €31.3 million.<sup>4</sup> Twenty-eight percent (28%) has gone to support partners that operate at international level; thirty-three percent (33%) has gone to support partners that operate at bilateral level, within countries; twenty-one percent (21%) has gone towards additional HIV-related activities; seventeen percent (17%) has gone towards management costs; and the remaining one percent (1%) is for pending requests.

Table 2 breaks the bilateral funding down by geographic area, showing that the largest portion of support (almost three-quarters) has been focused on Sub-Saharan Africa, followed by Latin America and the Caribbean. Table 3 breaks the bilateral funding down by technical area, showing that the largest portion of support has been focused on organizational and institutional development, followed by advocacy, knowledge management, and Human Resources development. Finally, Table 4 breaks down the bilateral funding by type of partner and shows that national CSOs and national governments top the list of recipients.

<sup>2</sup> The Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH was formed on 1 January 2011. It brings together the long-standing expertise of the Deutscher Entwicklungsdienst (DED) gGmbH (German development service), the Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ) GmbH (German technical cooperation) and InWEnt – Capacity Building International, Germany. For further information, go to [www.giz.de](http://www.giz.de).

<sup>3</sup> For more information (including how to request support) please go to BACKUP's website at [www.giz.de/backup](http://www.giz.de/backup).

<sup>4</sup> In 2007, BACKUP's contractual status within German Development Cooperation changed. This makes it difficult to compare earlier 2002-2006 data with the 2007-2011 data given here.

Table 2. Bilateral funding by region, 2007-2011

Area	Amount in €	%
Sub-Saharan Africa	7.538.100	74%
Latin America and the Caribbean	1.132.818	11%
Asia	677.496	7%
Eastern Europe and Central Asia	620.938	6%
Middle East and North Africa	219.636	2%
<b>Total</b>	<b>10.188.988</b>	<b>100%</b>

&gt;&gt; Source: German BACKUP Initiative

Table 3. Bilateral funding by technical area, 2007-2011

Area	Amount in €	%
Organisational/institutional development	2.976.524	29%
Advocacy	1.807.933	17%
Knowledge management	1.183.373	12%
Human resources development	1.124.763	11%
Monitoring & Evaluation	1.007.732	10%
Proposal development	925.881	9%
Policy/strategy/guidelines development	692.872	7%
Quality management	272.489	3%
Technical support needs assessment	197.422	2%
<b>Total</b>	<b>10.188.988</b>	<b>100%</b>

&gt;&gt; Source: German BACKUP Initiative

Table 4. Bilateral funding by type of partner, 2007-2011

Partner organisation	Amount in €	%
National CSO	4.418.965	43.4%
National government	3.341.537	32.8%
CCM	768.187	7.5%
Private sector	766.126	7.5%
International CSO	284.116	2.8%
Regional initiative	239.641	2.4%
Academic/training institution	234.627	2.3%
Multilateral PR	115.701	1.1%
Multilateral organisation	20.088	0.2%
<b>Total</b>	<b>10.188.988</b>	<b>100%</b>

&gt;&gt; Source: German BACKUP Initiative

## Case 1: The Civil Society Action Team

### The creation of CSAT



In 2005, the Global Fund and five of the co-sponsors of UNAIDS (UNFPA, UNICEF, UNDP, WHO, and the World Bank) established the Global Implementation Support Team (GIST) to help countries overcome bottlenecks preventing them from accessing and making effective use of Global Fund and other donor financing. In 2006, membership of the GIST was expanded to include ICASO, along with GTZ (now GIZ), the United States President's Emergency Plan for AIDS Relief (PEPFAR), International HIV/AIDS Alliance, International Coalition on AIDS and Development, and the Brazilian Centre for Technical Cooperation.<sup>5</sup>

In 2007, the GIST supported ICASO in a six-month consultation process through which it identified the specific needs of community-based CSOs for support building their capacity to participate in and benefit from Global Fund processes. The result was a proposal for a five-year (2008–2013) project to establish and operate the Civil Society Action Team (CSAT). UNAIDS and the German BACKUP Initiative have provided most of the support to implement the proposal, while the Open Society Institute, Canadian International Development Agency and Ford Foundation have also contributed.

Hosted by ICASO in Toronto, CSAT established seven Regional Hubs to better serve its intended beneficiaries. Identified in Table 5, these hubs were all existing organizations dedicated to representing and serving CSOs in their regions and were chosen on the basis of strengths identified during the 2007 consultations and 2008–2009 start-up months.

### Why an “action team”

The 2007 consultations leading to establishment of CSAT and further consultations during its 2008–2009 start-up months identified a series of challenges community-based CSOs are facing:

- Lack of adequate representation on CCMs;
- Lack of capacity to develop grant proposals;
- Lack of adequately trained project managers to implement approved proposals;
- Lack of adequately trained staff for financial management, monitoring and evaluation and reporting;
- Lack of adequately trained staff to support activities in local operations – for example, when a CSO managing a programme oversees other community-based CSOs delivering services on the front lines;
- Delays and unforeseen cut-backs in funding to CSOs serving as SRs of Global Fund grants.

Each of these broad challenges has diverse sub-challenges. For example, not having adequate representation on CCMs is a formidable obstacle that can only be overcome through determined advocacy from within countries and pressure from outside (notably from the Global Fund and its many international partners). Addressing the lack of capacity to develop grant proposals is essentially a “technical” problem, while tackling the lack of trained staff requires both capacity-building (to “train up” existing staff) and financial resources (to hire and retain better qualified staff). Finally, delays and cut-backs in funding involve issues of governance and of financial resources.

**Table 5: Regional CSAT Hubs (as of January 2011)**

Regional/Sub-Regional Hub	Host Organization
West and Central Africa	African Council of AIDS Service Organizations (AfriCASO), Senegal
Eastern Africa	Eastern Africa National Networks of AIDS Service Organizations (EANNASO), Tanzania
Southern Africa	Southern African AIDS Trust (SAT), South Africa
Middle East and North Africa	Association de Lutte Contre le SIDA (ALCS), Morocco
Asia Pacific	Coalition of Asia Pacific Regional Networks on HIV/AIDS ('7Sisters'), Thailand
Eastern Europe and Central Asia	Eurasian Harm Reduction Network (EHRN), Lithuania
Caribbean	Caribbean Vulnerable Communities Coalition (CVC), Jamaica

>> Source: German BACKUP Initiative

<sup>5</sup> Subsequently, GIST became known as the international working group for Coordination of AIDS Technical Support (CoATS) and, recently, CoATS was disbanded.



>> L. to r.: The Romanian Association against AIDS (ARAS) aims to reduce stigma and discrimination against Roma families like this one and, also, to improve their access to health services.

>> In Djibouti, people living with HIV and TB receive nutritional support from Iftin, a women's organization financed by the Global Fund.

### Box 3. Challenges facing CSOs working with marginalized populations

In recent years, it has become increasingly apparent that much of the money invested in the global response to AIDS has been misspent at all levels, from international to local. There are many reasons for this but the most persistent, over-riding reason has been that policies and programmes have not been based on sound evidence as to which populations are most vulnerable to infection and which behaviours make them vulnerable.

Contributing reasons include that a disproportionate share of the money available for international development since 2000 has been earmarked for AIDS, with the result that many organizations with little previous interest in the disease rushed to present themselves as legitimate AIDS service organizations in order to access the money. At the same time, CSOs representing men who have sex with men (MSM), transgender people, sex workers, injecting drug users and other most-at-risk or vulnerable populations were few, small and comparatively new, and often “muscle out” by more prominent organizations when applying for financial support.

A problem specific to CSOs representing MSM and transgender people is the fact that some 80 countries have laws forbidding male-male sex and recommending long prison sentences, corporal punishment or even death for anyone caught in violation of the law. These include most of the countries in sub-Saharan Africa and the Caribbean where HIV is most prevalent. The negative human rights environment sustained by such legislation has made it very difficult, if not impossible, for CSOs representing MSM and transgender people to organize openly or work in partnership with public health authorities, or even to do the research necessary to gather good evidence about how HIV impacts on MSM and transgender people. Similar problems face CSOs representing sex workers, drug users and other most-at-risk or vulnerable populations whose characteristic activities are often illegal.

Finally, there is still insufficient recognition of the essential role that community-based CSOs have always played in representing and serving the poor and marginalized. Even in high income countries with effective human rights protections, politicians and the general public are not sufficiently committed to the interests of the poor and marginalized. There is thus no guarantee that government-run programmes will serve them adequately or that organizations that can serve them adequately receive the necessary financing.

### What CSAT does

CSAT and its regional hubs serve as advocates for technical assistance for capacity building and, also, as brokers and coordinators of such assistance. Areas in which CSAT offers help include:

- Identifying needs for technical support to strengthen capacity;
- Identifying appropriate technical support providers;
- Identifying possible sources of financing for technical support;
- Advocating among technical support providers and financiers for more appropriate technical support;
- Coordinating CSO advocacy and other inputs to the Global Fund Secretariat, UNAIDS, WHO's UNITAID and other coordinating mechanisms;

- Promoting the inclusion of MSM, transgender people, sex workers, drug users and other marginalized and vulnerable groups in Global Fund processes, from proposal development to implementation.

CSAT emphasizes the setting of evidence-based priorities on a regional basis, which involves constantly assessing CSO needs. To set these priorities, CSAT's Regional Hubs collect data on the number and type of CSOs in their region, their needs for Global Fund financing, and their strengths and weaknesses and requirements for capacity-building so they can access that financing and put it to good use.

The following examples of the type of work CSAT carries out illustrate the range of needs and priorities that it responds to, and the broad scope of technical support it provides:



>> L. to r.: A community outreach worker at a mosque in Tajikistan, describes the symptoms of TB to a 19-year-old who then goes to a hospital and is diagnosed with TB. The mosque's outreach worker was trained by Red Crescent, with financing from the Global Fund.

>> The Lao Youth AIDS Prevention Programme (LYAP) works with the monks in this temple to raise HIV awareness, pray for people living with HIV and provide them with nutritious food.



- In partnership with the International Treatment Preparedness Coalition (ITPC), the **CSAT Hub in Eastern Africa** developed guidelines on CSO representation in CCMs. In Tanzania, these were used by the civil society delegation to the CCM to develop a Code of Conduct which has improved the coordination of CSO activities, expanded consultation and feedback among constituencies, and raised civil society's ability to speak with one voice and advocate for its own agenda.
- In 2010, the **CSAT Hub in Eastern Africa** carried out a survey of CSO needs. It used the results to advocate for more and better technical support to CSOs from governments and other development partners and, also, to inform a meeting with the regional Technical Support Facility to develop a partnership for technical support for CSOs and to develop technical support guidelines.
- The **CSAT Hub in West and Central Africa** supported establishment of a scheme called MentorPro. This project aims to facilitate mentorship from larger or more experienced CSOs to smaller or less experienced ones, especially those operating as Global Fund SSRs. MentorPro will be piloted in Nigeria and the Democratic Republic of Congo.
- One priority of CSAT in recent years has been to increase the inclusion of civil society issues in proposals to the Global Fund. This is done through direct support to CSOs involved in the proposal development process. For example, Zimbabwe was having difficulty finding affordable technical support as the deadline for Round 10 proposals approached. The **CSAT Hub for Southern Africa** stepped in, providing direct help to the national

drafting team, particularly in integrating Community Systems Strengthening into Zimbabwe's proposal.

- Another priority has been to increase CSO involvement in Global Fund governance and decision-making. For example, in Indonesia the **CSAT Hub for Asia Pacific** worked with the CCM to facilitate the selection of civil society PRs for the Round 8 proposal, which had a Community Systems Strengthening component. As a result, the Network of People Living with HIV was invited to join the CCM and to be included in the proposal.

## Challenges in the near term

Recently, CSAT completed a mid-term review in order to identify its strengths and weakness. In addition to providing an analysis of issues internal to CSAT, it identified external issues that resonate with the issues discussed elsewhere in this publication and point to the changing context in which the Global Fund and CSOs are operating.

A key issue is that donor countries are reducing their contributions to the Global Fund, as their own economies are caught up in the on-going global financial crisis. Currently, ICASO and CSAT are responding with advocacy (e.g., urging donors to honour commitments they have already made). However, they are also placing more emphasis on helping CSOs find alternative sources of financing and make the best possible use of whatever resources they already have. It is impossible to tell how this will eventually play out. In the meantime, CSAT continues to carry out the activities it was designed for.



>> L. to r.: In Callao, Peru, a local advocacy group for transgender people (including transgender sex workers) provides testing for HIV and STIs.

>> In Minsk, Belarus, the European Harm Reduction Network hosts a workshop teaching its member organizations about opiate substitute therapy (OST) for injecting drug users.

## Case 2: Burkina Council of AIDS Services Organizations and its contributions to Burkina Faso's response to TB

### Burkina Faso and its health challenges



Burkina Faso is landlocked, has no navigable waterways and few natural resources. Most of its population of 16.5 million people (UN, 2011) depend on subsistence and commercial agriculture but agricultural

production is under constant threat by low annual rainfall, frequent drought and inefficient agricultural practices. An estimated 82.6 percent of Burkinabe people are multi-dimensionally poor, meaning they are deprived in at least two of ten components of health, education and standard of living (UNDP, 2011). In 2007, 90% of Burkinabe adults 25+ years old had never been to school and only 36.7% of males (15+) and 21.6% of females (15+) were literate (UIS, 2011).

Burkina Faso's total spending on health per capita in 2009 was US\$88, about a third of which came directly out of patients' pockets. More than 20 percent of total spending came from international sources, so declines in development aid can have serious consequences (WHO, 2011). The health system was staffed by only 483 doctors, 2,757 registered nurses, 2,348 practical nurses and 833 midwives but there were far fewer per capita in most regions than in the country's two major cities (DGISS, 2010). To supplement their meagre public sector salaries, many also worked in the private sector.

In 2009, HIV prevalence was approximately 1.2 percent countrywide and there were 110,000 adults and children living with HIV (UNAIDS, 2010). In the same year, there were 4.4 million probable and confirmed cases of malaria in Burkina Faso and 7,982 deaths attributed to it (WHO, 2010). The estimated rate of prevalence of TB was 82 per 1,000; the estimated rate of TB incidence (new cases) was 55 per

1,000; the estimated rate of TB detection was 53 percent. Of notified TB cases in which HIV status was known, 18 percent were HIV-positive (WHO, 2011).

Since 2003, Burkina Faso has been awarded eleven Global Fund grants totalling US\$ 254 million: 50 percent for HIV/AIDS, 38 percent for malaria and 12 percent for TB.

### The creation of BURCASO

Established in 1991, the African Council of AIDS Service Organizations (AfriCASO) was the first of ICASO's five regional secretariats. In September 2001, it facilitated a meeting of Burkinabe CSOs in Ouagadougou and out of the meeting grew the Burkina Council of AIDS Services Organizations (BURCASO) or, as it is called in French, *le Conseil Burkinabé des organisations de lutte contre les IST/VIH-Sida*. By 2009, its membership had grown from the original 40 CSOs to 215 CSOs.

#### The current configuration

As is the case with most network associations of CSOs, some of BURCASO's members have substantially more financial and human resources than BURCASO has and many of them also belong to other associations of CSOs. There is overlap, for example, between BURCASO's membership and the membership of:

- the KASABATI association of CSOs representing and serving people living with HIV;
- the Union of Religious and Customary Burkinabe against AIDS; and
- the Coalition of Burkina Networks and Associations for AIDS Control and Health Promotion.

#### Box 4. German support for Burkina Faso's civil society organizations

Germany has been a bilateral partner of Burkina Faso since 1973 and, like many of Burkina Faso's other international partners, it has often supported initiatives that rely heavily on civil society engagement for their success. One such initiative is the ongoing GIZ-supported Programme on Sexual Health and Human Rights (PROSAD), fully described in an earlier publication (GHPC, 2009a).

The above mentioned and two other publications (GHPC, 2009b and 2009c) in this series describe a number of the highly creative and effective solutions CSOs in Burkina Faso and neighbouring countries have found to the problem of reaching into even the smallest, most remote villages with disease prevention, treatment and care.





>> Cécile Thiombiano-Yougbare, BURCASO's M&E Manager for TB, demonstrates the use of cartoons used for TB education in villages.

Under its constitution, BURCASO holds elections for its three senior officers every four years. To be eligible, nominees must be chosen from among the active members of BURCASO's member organizations. First elected by its General Assembly in August 2007, the current senior officers are Ouédraogo Ousmane, National Coordinator; Désiré Tassembédo, Head of Programmes; and Bilgo Mathieu, Head of M&E and Communications. Reporting to them are five additional staff members: the Financial Manager, the M&E Manager for the HIV Programme, the M&E Manager for the Tuberculosis Programme, Administrative Support Officer, and the Driver.

#### ■ Donor recognition and support

BURCASO received its first significant donor support (€70,000) in 2004 from the Netherlands Embassy and this gave it the capacity to advocate for civil society participation in Global Fund processes. A breakthrough came in 2005 when the Global Fund refused a Round 5 proposal from Burkina Faso's CCM but encouraged it to

resubmit after strengthening both the CCM and the proposal with more civil society participation. One result is that Burkina Faso's CCM has become one of the most broadly representative of all CCMs. Its 47 members include 16 from CSOs: the National Council of Customary Chiefs, three faith-based organizations, six representing people living with disease (PLWD) and seven others.

Another result of the Round 5 refusal was that the UNDP's Support Programme for Associations of Communities (PAMAC) – established in 2003 – became a Sub-Recipient (SR) of the Round 6 grant for HIV/AIDS and well-established as the main national mechanism supporting and coordinating civil society participation in the implementation of Global Fund grants in Burkina Faso. BURCASO became a Sub-sub-Recipient (SSR) of the Round 6 grant for HIV/AIDS one of four associations of CSOs supporting and coordinating CSO participation in implementation of Global Fund grants in Burkina Faso's 13 regions.

#### Box 5. How CSOs can help strengthen a weak health system

Dr Celestine Kinée Toé is Deputy Coordinator of Global Fund Projects for Burkina Faso's National Council for the Fight against AIDS and STIs. She explains that many health professionals strongly resisted sharing the country's extremely limited financial resources for health with CSOs. However, these limited resources meant they were taking a passive approach to HIV, responding only to patients who came to them with severe symptoms. With financing from the Global Fund, CSOs were able to reach out from the core health system with prevention. By 2006, they were also doing 95 percent of all testing for HIV and, thus, identifying HIV+ people before they were too ill to reap the full benefits of care and treatment. She says tuberculosis presents a similar challenge to over-worked health professionals. Burkina Faso's health system needs CSOs to deliver prevention and to encourage testing and adherence to treatment regimes.



>> L. to r.: Consultant Rakotosoa Herivola (seated at centre) teaches staff from three CSOs acting as BURCASO's Regional TB Coordinators how to use the M&E software and other tools they have helped him develop.

>> At Centre Nord's regional hospital in Kaya, members of L'Association Yam Waya (three of whom pose with a nurse) have all had TB and provide support to new TB patients and their families.

## Three rounds of BACKUP support for BURCASO

In 2009, BACKUP became a partner providing technical support to BURCASO. Between then and 2011, BURCASO received and implemented three grants from the German BACKUP initiative totalling €52,000 to help it build capacity to meet its challenges.

### ■ First grant: integrating reproductive health into Round 9 HIV proposal

In April 2009, with €9,500 from BACKUP and additional support from Population Action International (PIA), BURCASO was able to organize and host a two-day workshop attended by representatives of 52 organizations, including CSOs, the Directorate of Family Health, the National AIDS Council, PAMAC, GTZ-PROSAD and other stakeholders. All of the attendees were involved in advocating for – and some were involved in drafting – a proposal to include reproductive health into a marginalized and vulnerable communities component in the HIV part of Burkina Faso's Round 9 proposal to the Global Fund.

While the proposal was rejected by the Global Fund, the workshop had been an opportunity for participants: to share their experiences in implementing Global Fund grants; to discuss ways in which they might strengthen their partnerships with government organizations; to discuss ways of strengthening their mechanism for consulting with each other; and to become more aware of the advantages of integrating reproductive health into their HIV advocacy. The workshop also raised BURCASO's profile and enhanced its credibility and capacity as an organization able to mobilize CSOs prepared to contribute to improving the health of the Burkinabe people.

### ■ Second grant: building CSOs' project and financial management capacity to implement Round 8 TB project

The five-year (2010–2014) Round 8 TB Project is overseen by PAMAC, the PR. BURCASO is one of three SRs and, as such, oversees the work of 65 CSOs in six of Burkina Faso's

13 regions. To build their collective capacity to implement their part of the Project, BURCASO applied for and received a €18,500 grant from BACKUP. This enabled BURCASO to pay a consultant for 60 days stretched over six months, from 1 April to 30 September 2010, and provide technical support for a process that involved assessing the capacity of each CSO to manage its part of the project, facilitating a workshop to consider a draft report on the results of this process, acquiring equipment (including computers) and developing tools to help staff improve project and financial management, and supporting staff as they began using the tools. BURCASO reports that, as a result, they now have a good financial management system in place.

### ■ Third grant: building CSOs' monitoring and evaluation capacity in support of the implementation the Round 8 TB project

With another €24,000 from BACKUP, BURCASO has recently implemented the first phase of a three-phase project that, when fully implemented, will cover all of its member CSOs with an effective monitoring and evaluation (M&E) system whether or not they are engaged in Global Fund processes. The first phase (1 July to 31 December 2011) focused on three of the regions (North, Plateau Central, Sahel) in which BURCASO oversees implementation of the R8 Global Fund TB project. It involved work with the three CSOs designated as Regional Coordinators, notably a workshop to discuss and agree on all of the M&E indicators that should be taken into account and, thus, the data the system should collect and analyze. The basic indicators were taken from the M&E system established by the National AIDS Council, which, in turn, included the indicators required by the Global Fund. Particularly relevant are indicators and data measuring the extent to which the allocated resources allow them to carry out their assigned tasks to the fullest extent possible. For example, the data show that allocations from the Global Fund fall short of covering BURCASO's member CSOs' costs for the office space, furnishings, equipment, supplies, and transportation they would need if they were to contribute as much as they possibly could to the response to TB.



>> Two actors from GASCODE's forum theatre troupe perform a short play about TB in the central market of Ziniaré, regional capital of Plateau Central.

BACKUP has financed only the first phase of this three phase M&E project but it has enabled development of a strategic plan for M&E which calls for the training and support of designated M&E focal persons for all the CSOs that serve as BURCASO's coordinators in each of the country's 13 Regions. Other activities covered by the BACKUP funding included:

- Development of all the tools required to collect, analyze and report data (e.g., hard-copy forms for manual entry of data on site, software with electronic forms for data transfer);
- Improvement of systems and procedures for archiving data and making them readily accessible;
- Training for staff of BURCASO and three CSOs acting as regional coordinators in use of the tools and software, including use for quality control (e.g., ensuring implementing CSOs are carrying out their assignments and producing good results); also, training in archiving;
- Providing monthly support to all staff to make sure they are doing all of the above properly and with no great difficulty and either provide more instruction or modify the tools and procedure;
- An end-of-first phase assessment.

### BURCASO's participation in the Round 8 TB Project

Burkina Faso's R8 TB Project has a five year (2010-2014) budget of €20.8 million, and 25 percent of that total is allocated to CSOs. For the CSO allocation, the UNDP's PAMAC acts as PR and three organizations – BURCASO, KASABATI and URCB/SIDA – act as SRs. BURCASO is responsible for overseeing the participation of 65 its member CSOs in the country's six easternmost regions: Est, Sahel, Plateau Central, Centre Nord, Centre (with the country's capital, Ouagadougou), and Nord.

In each region, through a competitive process, BURCASO has chosen one of its CSOs to act as Regional Coordinator; two CSOs of people who have had TB in the past and are prepared to support current TB patients and their families

through treatment and care; depending on the region's population, anywhere from 6 to 14 CSOs that focus on prevention (e.g., with animations in villages) and on identifying people with symptoms and referring them to hospitals or health centres for testing (often done during animations). BURCASO's budget allocation (€485,000 for the first two years of the R8 TB Project) has allowed it to engage only 57 CSOs in prevention, though it had estimated that it would need twice as many, and has allowed it to train only two animators per CSO, though it had estimated that it would need six animators per CSO. This means there is only one animator for every twelve BURCASO estimated it would need.

### Challenges on the front lines

The *Groupe d'Appui en santé, communication et développement* (GASCODE) is one of BURCASO's six Regional Coordinators for the Round 8 TB Project, responsible for Plateau Central. As its name implies, GASCODE focuses on health issues (HIV, malaria, sexual and reproductive health, family planning, etc.) but it also addresses illiteracy, human rights and other issues that impact on health and it runs an orphanage. An October 2011 visit to its office Ziniaré, the capital of Plateau Central, provided an opportunity to identify the limitations of the Round 8 TB Project and the major challenges it poses. These include:

- The Project allocates CFA 60,000 (€90) every three months to each Regional Coordinator to pay for its office, equipment, supplies and operations. GASCODE's electricity bill for its office in Ziniaré comes to CFA 70,000 every three months. The Project allocates CFA 20,000 (€30) every three months to each implementing CSO to pay for its office, equipment, supplies and operations. Some CSOs feel they don't need an office but the Project requires that they have one anyway, so they waste some of their small allocation on renting the cheapest space they can find.
- The Project provides CFA 2,400 (€3.95) for animations and similar events in villages and also provides CSOs with two bicycles each for transportation. Volunteers often have to travel 50 kilometres or more to stage animations and, whether they use the bicycles or their



>> Cécile Thiombiano-Yougare (seated in foreground) watches a village animation during one of her M&E missions for BURCASO.

own mopeds, there is no insurance to cover their expenses if they run into difficulties.

- There is no budget for BURCASO or its CSOs to prepare their own IEC material for animations. Instead, the material they have is provided by the national TB programme, but it is not sufficiently interesting to engage the attention of villagers during presentations. There is no provision for audio-video material or equipment such as radios, televisions and portable electricity generators.
- Extreme challenges and lack of compensating incentives make it difficult to retain the trained animators. Plateau Central is the least populous of the six regions covered by BURCASO and so has only 6 CSOs that focus on prevention, identifying people with symptoms and providing them with referrals. These 6 CSOs started the Project with a total of 12 trained animators but have already lost 5 of the most talented ones to jobs in government and the budget does not provide for training of replacements.

The problems at the frontline are mirrored by those faced by BURCASO in its coordinating role. It has only one vehicle with one driver for everything it does, and fuel is expensive. Its three senior officers and other staff and consultant are able to do few site visits, and they tend to wait until there is enough business at one site to give several of them reason to travel together.

## The way ahead

Notwithstanding all such challenges, BURCASO and its member organizations say they are strongly committed to making the R8 Global Fund TB Project work, and they prove it through their work. They point out that CSOs in Burkina Faso have to be multi-functional and entrepreneurial and that they are given more support for some projects than others. In GASCODE's case, for example, they get far more support from UNFPA and UNICEF to support their work against female genital mutilation than they get from the R8 Global Fund TB Project for their work against TB.

During a visit by the writer of this publication to one of the CSOs working with BURCASO in Plateau Central, a staff member referred to GIZ and its BACKUP Initiative as an "angel of mercy". Like other stakeholders interviewed for this publication including national programme officials, and BURCASO staff, this staff member felt that without BACKUP's support, it is probable that BURCASO would not have qualified as an SR overseeing the Project in six of the country's 13 regions, and they would not have learned how to manage their part of the Project nearly so well and put in place the M&E system they are still in the process of establishing. Asked what would be their number one priority for further assistance they were unanimous in mentioning things that would help them get more of the financial and technical support they feel they need.

### Box 6. Having ready access to technical support would be ideal

Ousmane Ouédraogo is the National Coordinator of BURCASO and says that, ideally, BURCASO and its member CSOs would have ready access on a continuing basis to an independent technical support provider, such as GIZ, that has offices in Burkina Faso or nearby. Such support could help them identify and respond to challenges and opportunities as they emerge and, also, build up an ever better body of evidence on which to base their actions and ever greater capacity to carry out those actions effectively.



## Case 3: Youth in the Real World and its contributions to the Dominican Republic and Caribbean responses to HIV

### The Caribbean, where official denial is a major challenge



The Caribbean region has long had the world's second highest HIV prevalence. However, there is considerable variation in prevalence levels, trends and patterns across the region.

Down through the years since the epidemic emerged, there have been small studies scattered across the region showing that many people belong to most at risk populations (MARPs) and other vulnerable populations (OVPs) and that HIV prevalence is very much higher among these populations than it is in the general public. However, there has been much official denial surrounding behaviour that puts those populations – and indirectly the general population – at risk: men having sex “on the down low” (i.e. they deny having sex with men but openly engage in sex with women); anal sex in heterosexual situations; local men (not tourists) often accounting for the majority of the clients of sex workers; the sexual exploitation and abuse of under-aged youth, including in the sex work industry; young adults often engaging in transactional sex; systemic racism that denies HIV prevention and other services to second and third generation immigrants.

As a result of official denial, there has been little research on the populations and behaviours that give Caribbean countries such high rates of HIV infection. In the absence of good evidence, programmes to prevent HIV transmission have not been well-targeted and governments have been slow to reform laws and create human rights environments where people are less afraid to admit what they actually do and health care providers are more inclined to provide non-judgmental and compassionate care to everyone.

With the exception of low-income Haiti, all countries in the Caribbean are lower-middle or upper-middle income, yet their governments contribute very little to their national responses to HIV. Across the Caribbean region, total expenditure on HIV during the 2008-2009 budget year came to an estimated US\$ 497 million but only 31 percent of that total was domestic spending (by government, local CSOs and out-of-pocket by PLWHIV and their families). By contrast, 64 percent came from the Global Fund and bilateral donors, 4 percent came from multilateral organizations (e.g., UNAIDS, WHO) and 2 percent came from other international donors (Camara, 2011).

### Dominican Republic: comparative success despite low spending

In Dominican Republic, HIV prevalence has remained comparatively low, with the estimated annual number of new infections falling from 4,900 in 2001 to 3,600 in 2009 (UNAIDS, 2010). However, AIDS remains the leading cause of death among adults, and there is evidence that HIV prevalence among MSM may be increasing.

There is also concern that past gains could be quickly reversed as financing for the HIV response decreases. Spending on HIV prevention in Dominican Republic declined from an already modest US\$11 million in 2007 to US\$5.5 million in 2009 and will decline further if international donors continue to reduce their contributions (Camara, 2011).

### The creation of YurWorld

YurWorld (from Youth in the Real World, or “Jóvenes de la Vida Real” in Spanish) was born out of a proposal to establish Ideas Youth Café, a youth centre with outreach programmes in Santo Domingo, and, ultimately, similar centres in other large cities across the Dominican Republic. The proposal took shape during the four-year (2003-2006) ex-GTZ Supra-regional Project “Youth and AIDS in the Caribbean” (ProSuRe-GTZ). The Ideas Youth Café and ProSuRe-GTZ are described at length in “German contributions to the Caribbean AIDS response” (GHPC, 2008).

The Ideas Youth Café was conceived during a series of *tertulias*, a traditional Spanish method of engaging all elements of a community in discussion and debate. Among the regular attendees were members of Red Nacional de Jóvenes (National Network of Young People), the country's main network of youth and youth organizations concerned with sexual and reproductive health. Conspicuously present was a small group of very young gay, lesbian and bisexual friends who called themselves Los Muchachos y Muchachas de la Mesa de Atras (Boys and Girls at the Back Table) because they had grown accustomed to finding each other at a back table in a particular café that made them feel welcome. Also often present were members of Jóvenes por Siempre (Forever Young), a CSO for young people living with HIV that grew out of the Alianza Solidaria para la Lucha contra el VIH (Alliance for Solidarity in Action against AIDS), a CSO for anyone living with HIV.



>> L. to r.: From Guachupita, one of the poorest barrios in Santo Domingo, these trainees are in the first class of 109 to attend YurWorld's 12-week course for peer educators.

>> Questionnaires help determine what trainees know about HIV and other sexually transmitted disease before they begin the 12-week course.

In 2004, with support from ProSuRe-GTZ, the young attendees formed a committee and drew up plans for a youth centre with a café. By the fall of 2005, the committee was ready to launch the Ideas Youth Café on a trial basis using the ProSuRe-GTZ's offices as its venue on Thursday through Sunday evenings and Saturday and Sunday afternoons. The ProSuRe-GTZ project came to an unexpected end in early 2006, for policy and administrative reasons that in no way reflected on the hard work, commitment and achievements of any of the young people involved.

Though the committee and others involved in the youth centre/café were disappointed, at a meeting they agreed that their whole experience with ProSuRe-GTZ had been a very positive one. It had provided them with skills to network, advocate, do research, plan and manage projects, and monitor and evaluate the results. It had also given them opportunities to travel and attend Caribbean and international conferences where they learned what other young people were doing to respond to HIV and were inspired by their examples. Most importantly, they were left feeling determined that, somehow, they would carry on.

#### ■ An established CSO steps in

El Centro de Orientación e Investigación Integral (COIN) – in English, the Center for Integrated Training and Research – was launched in November 1988. Since then, it has provided education and prevention services in sexual and reproductive health and HIV/AIDS for marginalized populations, including sex workers, MSM, youth in particularly difficult circumstances, domestic workers, and migrant and trafficked women.<sup>6</sup> It has a long tradition of helping MARPs and OVPS found their own organizations, link with each other and launch joint programmes with COIN.

Dr John Waters, a medical doctor who often worked in COIN's clinic and participated in ProSuRe-GTZ, had helped with the *tertulias* that led to the Café. After ProSuRe-GTZ came to an end, the committee of young people continued to engage with COIN and its partners. In early 2008, they agreed to establish a new COIN project called *Jóvenes de la*

*Vida Real* or Youth in the Real World (YurWorld) and base it on concepts underlying the Ideas Youth Café and ProSuRe-GTZ. Specifically, the project would move forward with developing a youth centre along the lines of Ideas Youth Café, with outreach programmes and, eventually, with similar centres or, at least, programmes in other major Dominican cities.

#### ■ A boost from BACKUP

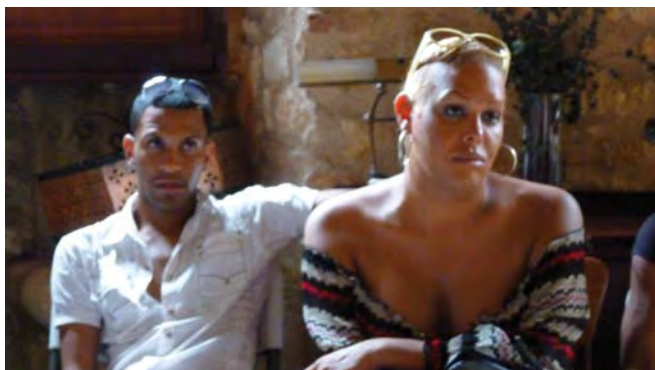
By July 2008, COIN had developed a final proposal for YurWorld and negotiated an agreement with the German BACKUP Initiative that included a financial contribution of €61,000 and a ten-month (July 2008 to May 2009) schedule of activities. UNAIDS and many other partners would make financial or in-kind contributions, too, but €61,000 would be the core budget. The objectives were:

1. To build the capacity of youth and their formal and informal organizations and empower them to participate in the response to HIV in the Dominican Republic and, by example, to HIV in the whole Caribbean region;
2. To build the capacity of "key stakeholders" (i.e., youth and their formal and informal organizations) to forge partnerships with "key duty-bearers" (i.e., adult-run organizations driving the HIV response) and to collaborate with them on advocacy and proposal development (including for the Global Fund), and on implementing approved proposals effectively;
3. To facilitate input by youth into national and regional mechanisms for setting HIV policy, coordinating implementation and allocating resources;
4. To advocate for and participate in research to provide the evidence-base for the response to HIV among youth.

#### ■ Tertulias de Jóvenes: the central mechanism driving the project forward

The YurWorld project resumed the monthly *tertulias* under the title of *Tertulias de Jóvenes*. Now, however, they were more focussed on bringing key stakeholders together with key duty-bearers and having them collaborate, first, on reaching a better understanding of HIV among youth and, second, on how to mobilize resources to prevent it.

<sup>6</sup> Centre for Integrated Training and Research, "History", at <http://www.coin.org.do/Idioma/english/history.html>



>> Aligned with YurWorld, COTRAVEDT supports “Wednesday with Mama”, a weekly transgender support group facilitated by a 55-year-old transgender woman.

Key duty-bearers attending (e.g., representatives of the Presidential AIDS Council – COPRESIDA) made sure that the *tertulias* were informed by the most up-to-date evidence available, including the 2005–2006 behavioural surveillance surveys (BSSs) in six countries of the Organization of Eastern Caribbean States. Key findings of the BSSs were that social connections through school and family are strong factors preventing HIV infection among youth, while being out of school and experiencing physical or sexual abuse are strong factors putting youth at risk of infection (CAREC et al., 2007). Also taken into account was a 2008 BSS in Dominican Republic which found HIV prevalence of 6.1 percent among MSM, 4.8 percent among female sex workers and 8 percent among drug users, with considerable variation across the country. It also found high percentages of young adults (15–24) in all three MARPs – especially MSM – and considerable overlap between MARPs. That is, transgender people were often sex workers and sex workers were often drug users (COPRESIDA, 2009).

These results supported the conclusion that effective responses to HIV among youth should focus less on school programmes and more on out-of-school programmes and should focus, in particular, on youth belonging to MARPs and OVPs. They also supported the conclusion the CSOs representing and serving MARPs and OVPs (including youth within them) are essential partners in research into the dynamics of a country’s HIV epidemic and in identifying and implementing effective responses.

#### ■ Building partnerships and credibility

The YurWorld project was launched at a critical turning point in the global response to HIV. The European Union (EU), the Organization of American States (OAS), UNAIDS, the Global Fund and other international partners were, at last, really listening to the CSOs representing MARPs and OVPs and responding with policy changes.

In the Dominican Republic, many partners in the response to HIV were looking for opportunities to work with MARPs and OVPs just as YurWorld offered them such an opportunity. Some of the key partners that attended the *Tertulias de Jovenes* on a regular basis or that participated in its various

offshoots (described below) included UNAIDS, the government agencies COPRESIDA and Division for Controlling STIs and HIV (DIGECITTS), and the Red Nacional de Jóvenes (RNJ), which holds a voting seat on the CCM that oversees Global Fund processes.

In addition, twelve formal and informal organizations representing youth among MARPs and OVPs in Santo Domingo and a total of 50 such organizations across the country became core attendees at the *Tertulias de Jovenes* and at consultation meetings and workshops across the country. Together with RNJ, these Dominican youth organizations also networked with regional and international youth organizations at every opportunity.

#### ■ Rapid “learn-as-you-do” capacity building

The *Tertulias de Jovenes* forged new partnerships ready to act so quickly that much of the capacity-building activity was learn-as-you-do, though often supported by training workshops financed or hosted by BACKUP, UNAIDS, PAHO, COIN and other partners. These training workshops provided around 150 leaders from 50 youth organizations across the country with skills at networking, forging partnerships, advocating for action, doing research to gather evidence, developing proposals, managing projects, administering budgets, monitoring and evaluation, and reporting results.

The COIN/YurWorld team was happy to let willing partners use YurWorld as a vehicle, so long as the partners’ objectives aligned with their own. It meant the partners were often setting priorities, by agreeing to support some interventions but not others. However, the team hoped they would be able to get support for a more balanced set of projects and programmes and realize their vision of a multi-functional youth centre with outreach programmes in Santo Domingo and similar centres in the Dominican Republic’s other large cities.



>> L. to r.: Executive Director Santo Rosario Ramirez explains how COIN identifies and empowers natural leaders in marginalized populations.

>> Now deceased, Carmen was a sex worker who trained as a peer educator and, as shown here, helped educate the Dominican Republic's Presidential AIDS Council (COPRESIDA) about HIV among sex workers and their clients.

## Activities since the BACKUP-supported start-up phase

The COIN/YurWorld team now describe the ten 2008-2009 months during which BACKUP supported them as a crucial start-up phase. Without it, the momentum from the Ideas Youth Café would have been lost, the group of young people assembled around the Café would have dispersed and COIN would not have been able to get nearly so involved. Since that start-up phase, YurWorld has attracted support from many partners and launched a number of initiatives, some of which are:

- **Centro Salud Joven (CeSaJo)**, the Youth Health Centre, was established in the Colonial Zone in late 2009 and was recently moved to larger premises just outside of the Zone. Licensed as a primary health care centre, it provides friendly health services to marginalized and vulnerable youth and serves as YurWorld's headquarters. At time of writing, a five-year Global Fund Round 9 contribution totalling US\$300,000 is coming on-stream and providing core funding for the premises and for basic youth-specific programmes. Already well underway is a series of 12-week courses to train peer educators in an "I choose my life" approach, emphasizing building self-esteem and giving youth the knowledge and skills to make their own choices. The first class consisted of young Haitian immigrants from a Santo Domingo neighbourhood where many Haitians live.
- **The Tal Cual health programme for transgender women** (biological males who self-identify as females) – run jointly by Comunidad de Trans Trabajadoras Sexuales Dominicanas (COTRAVEDT) and YurWorld – provides prevention information and outreach services to Santo Domingo's estimated 4,000 transgender women, many of whom are sex workers. It is supported by grants from the American Foundation for AIDS Research (amfAR), the French Development Agency, UNDP, and the Heartland Alliance for Human Needs and Human Rights.
- **YurWorld's programme for MSM who do not self-identify as gay** works with several populations: male sex workers, most of whom consider themselves heterosexual; men who say they are not gay or bisexual but who come to health clinics with injuries or other symptoms of same-sex activity; clients of male sex workers who do not self-identify as gay or bisexual and are sometimes married or have girlfriends. Supported by a grant from amfAR, this programme aims to understand and meet the needs of these men for HIV-and-STI-related services.
- **YurWorld's work with youth engaged in transactional sex and female sex workers** includes the production of a documentary film (*Buscándomela*, or "Getting By") – financed by a grant from the Caribbean Treatment Action Group (CTAG) – about transactional sex along the south coast of Dominican Republic. Further afield, YurWorld has helped produce a series of radio programmes aimed primarily at female sex workers in Antigua, with financial support from UNFPA. YurWorld and COIN are expanding activities in this area due to the fact that Dominican women are disproportionately represented among female sex workers throughout the Caribbean, as well as in the rest of the Americas and Europe.
- **YurWorld's programme for drug users** began in 2009 with a grant from the CTAG. HIV prevalence is 8 percent among drug users in Dominican Republic and many drug users, male and female, support their habits by engaging in sex work (BSS, 2008). Activities include health outreach with counselling, testing for HIV and STIs, and onward referrals; sensitizing staff at the selected care and treatment centres to which they are referred; training drug users as peer educators and providing them with prevention literature and supplies. A three-year project started in October 2011, financed by the Centers for Disease Control (CDC) and for which YurWorld is the principal recipient, is expanding peer education to cover more drug users, first in Santo Domingo and then in other cities.



## The way ahead

In interviews held in November 2011, managers and key staff members of COIN and its YurWorld project were unanimous in their view that the ten-month (2008-2009) start-up phase, financed mainly by the BACKUP Initiative, had succeeded beyond all expectations. This was partly a matter of timing but it also demonstrated the strengths of COIN's horizontal approach to community development, which involves identifying strongly committed natural leaders among MARPs, OVPs and youth and then empowering them with knowledge, skills and on-going guidance and support. Three years after that start-up phase, YurWorld is a vigorous project with many activities underway, and many in the planning or negotiation stage.

Looking towards the future, the YurWorld team notes that despite their many successes, they have been unable to implement their central vision: the implantation across the Dominican Republic of multi-functional youth centres with outreach programmes that empower marginalized and vulnerable youth. In the years ahead, they hope to convince some of their existing partners that this is a vision worthy of their support and to find new partners. They believe it will be important for YurWorld to keep moving towards this vision and not allow partners, however well-meaning and generous, to divert them and turn them into a vehicle for one short-term project after another.

Too often, COIN and its YurWorld project are obliged to postpone or not carry out work that addresses their own priorities while doing work that addresses the donors' priorities. For example, donors strongly encourage and support the collection of statistical data but not of the qualitative data necessary to really understand the needs of vulnerable youth and to measure the impact of programmes on them. Similarly, donors have little interest in mental health, while COIN and YurWorld believe that the most pressing health need of many vulnerable youth is for psychological and social support.

As a final thought, the representatives of COIN and YurWorld interviewed for this publication emphasize the continuing problem of getting funders to draw the logical conclusions from available data about HIV transmission in Dominican Republic, and indeed in the region. Despite epidemiological evidence that male-male sex is a major contributor to HIV, donors continue to have very little interest in MSM of any age, including young MSM. It is the hope of YurWorld and COIN that substantial, multi-year funding may yet be found to understand and address the needs of this vulnerable group, and in doing so finally come to grips with HIV in the Caribbean.

### Box 7. The CVC/COIN Vulnerabilized Groups Project

When the BACKUP-supported start-up phase of COIN's YurWorld project got underway in July 2008, PANCAP had already begun an extensive consultation process with 50 stakeholder groups around the Caribbean and had given them a deadline for submitting proposals for inclusion in PANCAP's Round 9 Global Fund proposal. The *tertulias* and other processes associated with YurWorld brought COIN into close contact with the Caribbean Vulnerable Communities Coalition (CVC) and they decided to pool resources and submit a joint proposal for a Vulnerabilized Groups Project that would address the needs of MARPs and OVPs and would have a Marginalized Youth component.

As a result, Dr John Waters is now Programme Manager of the CVC/COIN Vulnerabilized Groups Project 2011-2015. A component of the PANCAP Round 9 Global Fund Project 2011-2015, it has been allocated one third of the total five-year budget of US\$34.5 million. Dr Waters explains, "the CVC/COIN component has a Marginalized Youth sub-component, which has been allocated a five-year budget of US\$2.2. This component is administered by YurWorld and it aims to develop models of good practice in the Dominican Republic, Jamaica, and Trinidad and Tobago during its first phase. In its second phase, the activities will expand to cover an additional three countries."

Asked about the involvement of the young people who are at the heart of YurWorld, Dr Waters reflects, "it all started back in 2003 with GTZ's 'Youth and AIDS in the Caribbean Project' (ProSuRE) and with the enthusiastic engagement of youth like Elias Ramos. He was a member of Boys and Girls at the Back Table back then, and he is now YurWorld's Project Manager. He remains absolutely determined to realize the dream of a multi-functional youth centre that was born out of ProSuRE and its *tertulias*."

## Lessons learnt from CSAT, BURCASO and YurWorld

Lessons learnt from the experience of BACKUP in supporting CSAT, BURCASO and YurWorld include:

- **Community-based CSOs are often best placed to represent and serve marginalized and vulnerable populations at the front lines of disease, but they need support to do this effectively.** National, regional and international CSOs or networks of CSOs can help community-based CSOs marshal financial and technical support and achieve economies of scale by facilitating coordination and collaboration – for example, in developing models and tools that can be adapted to local situations. They have particularly strong roles to play in helping community-based CSOs create climates of understanding and tolerance, where internationally recognized human rights become locally recognized human rights. The BACKUP approach to providing demand-driven and flexible technical support to CSOs at all levels, from international to local, recognizes this mutually-reinforcing ecology of CSOs and responds to it.
- **Support must be flexible and timely, responding to challenges and opportunities as they emerge.** The CSAT experience shows that opportunities arise unexpectedly, e.g. when alternative funding channels are blocked or technical difficulties are experienced. The ability to make funding decisions quickly is important in any effort to support CSOs.
- **CSOs are eager and well able to benefit from the type of capacity-building that BACKUP supports.** The evidence from BURCASO and YurWorld shows that the capacity of CSOs to take external advice, analyse their needs and strengths, and work with other organizations is high, and that this results in solid – and ultimately successful – contributions to Global Fund processes. This practical evidence coincides with the Global Fund's own research (described in the first section of this document) into grant effectiveness, which puts CSOs at the top of the ranking of organizational effectiveness in implementing grants (i.e. as measured by grants meeting or exceeding expectations).
- **Staying the course pays off in the long run.** There is value in continued interest in worthy CSOs and their programmes and, when the moment is right, providing them with additional support even when earlier support was not entirely successful. The first BACKUP grant to BURCASO in 2009 did not result in the Round 9 Global Fund support they hoped for. However, BURCASO learned from the experience, and two additional BACKUP grants have improved its capacity to perform as SR of a Round 8 TB Project. Similarly, when COIN approached BACKUP with its proposal for the YurWorld project in 2008, it was demonstrating that young people remained keen to pursue the objectives they had set for themselves four years earlier and were not defeated by a funding setback experienced in 2006. BACKUP's support helped their past efforts come to fruition.
- **Support for CSOs often has knock-on benefits.** As seen in the examples of BURCASO's member organization GASCODE and in COIN and its YurWorld project, many CSOs are multi-functional and not exclusively or even primarily devoted to doing the things the Global Fund and other donors are devoted to supporting. While this sometimes complicates donor-recipient relations (since funding streams tend to have narrowly defined objectives), multi-functionality allows CSOs to achieve economies of scale, indirectly using resources they have for one programme to support their other programmes. It also helps them survive the highly capricious nature of international development, with project-oriented donors who are seldom in for the long haul and who might withdraw at any time due to political and economic circumstances back in their homelands.
- **During times of cut-backs in development aid, CSOs should not be pushed to the back of the line.** The examples in this publication illustrate that the strengths of CSOs come to the fore in settings where resources are limited and governments are unable or unwilling to provide essential health services to everyone. When resources are cut back even further due to cut-backs in development aid, donors should keep these strengths in mind and continue to give high priority to providing financial and technical assistance to CSOs that can legitimately claim to represent and serve the poor and otherwise marginalized and vulnerable in their regions, countries and communities.

## Peer review

Based on the information provided in this publication, two independent peer reviewers have assessed the BACKUP approach to supporting CSOs against the eight criteria for the German Health Practice Collection (GHPC) and have found it to be “good or promising practice”.

They cited BACKUP’s support for YurWorld as a “wonderful example of best practice” in strengthening the capacity of marginalized groups to participate in the response to HIV and other health conditions in countries and regions with weak human rights legislation and enforcement. BACKUP, they said, has made “a valuable contribution” to giving voices to CSOs working with marginalized groups, and to facilitating their participation in Global Fund and other donor mechanisms and processes at all levels, from international to local.

They said that BACKUP’s resources “have clearly been allocated to the areas of greatest need” across the world’s regions, across the three diseases on which the Global Fund focuses, and across the categories of partners. They commended it, in particular, for allocating a large share of its resources to CSOs and for making significant contributions to the fact that Global Fund assessments find that CSOs are, on average, the highest performers among all categories of Principal Recipients.

Applying the eight GHPC criteria, the two reviewers found:

### Effectiveness

To be effective, CSOs often require technical support in a broad range of areas. BACKUP is “at the cutting edge” of providing such support to CSOs that benefit or hope to benefit from Global Fund financing.

### Participatory and empowering

The three case studies illustrate BACKUP’s commitment to empowering the poor and otherwise marginalized and vulnerable and supporting their sustainable participation in efforts to strengthen health systems and ensure those systems provide essential services to everyone.

### Transferability

BACKUP’s demand-driven and flexible approach to providing technical support comes close to defining the meaning of “transferability.”

### Gender awareness

The three case studies do not happen to focus on BACKUP’s well-known support for CSOs representing or serving women and girls. The Youth in the Real World (YurWorld) case study, however, illustrates BACKUP’s recognition that – in the real world – “gender” is not only about two genders, each of which engages only in opposite-sex activity. Individuals define their own genders in many different ways and effective responses to HIV and STIs are based on respect, understanding and compassion for individuals.

### Quality of monitoring and evaluation

This publication shows that community-based CSOs representing the poor and otherwise marginalized and vulnerable are often strong advocates for evidence-based responses to disease. They want technical support for monitoring and evaluation and for special studies providing evidence on which to base actions and against which to measure results. A great deal of money gets wasted because governments and their international partners are not always so demanding of evidence. The two reviewers suggest that the Global Fund, ICASO and BACKUP (and their own organizations) consider commissioning independent evaluations to determine to what extent their support goes to those public, civil society and private partners whose responses to disease are based on good evidence.

### Cost-effectiveness

The case studies show that CSOs are often sufficiently dedicated that they will carry on trying to serve their target populations regardless of whether or not they have sufficient resources to do this well. Modest contributions from BACKUP can give them the “little bit extra” they need to achieve impressive results.

## Innovation

BACKUP's demand-driven and flexible approach also embraces and encourages innovation. YurWorld's *Tertulias de Jovenes* bringing "key stake-holders" (e.g., CSOs representing marginalized youth) together with "key duty-bearers" (e.g., the Presidential AIDS Council) in efforts to understand and respond to HIV among youth is a particularly interesting example of innovation.

## Sustainability

This publication shows that CSOs are often sustained by the strong commitment of their members and volunteers. Their commitment would seem to be matched by the commitment of BACKUP to support them. It is to be hoped that this commitment will remain in the years ahead, even as the Global Fund and BACKUP's other international partners adjust their policies and programmes to fit ever changing circumstances. The flexible BACKUP approach to providing technical support allows it to adapt to change and sustain its support for community-based CSOs.

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