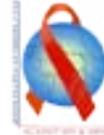




Caribbean
Vulnerable
Communities
Coalition



CARIBBEAN CIVIL SOCIETY SHOWCASE SERIES

Showcasing projects and programmes supported by the CVC/COIN Vulnerabilised Groups Project and aiming to strengthen rights-based responses to HIV in the populations most vulnerable to HIV

Monitoring Services for Youth Living with HIV: A community monitoring programme run by youth living with HIV



REDNAJCER has been lobbying Social Security for inclusion of anti-retroviral therapy (ART) in the social security law. REDNAJCER's President, Felix Reyes, wears a t-shirt that reads, "A State that does not guarantee my rights makes me more vulnerable to HIV/AIDS." Photo: Fran Afonso

In the Dominican Republic, Monitoring Services for Youth Living with HIV is implemented by **La Red Nacional de Jóvenes Viviendo con VIH/SIDA (REDNAJCER)** – "The National Network of Youth living with HIV/AIDS". REDNAJCER was formed to increase the participation of youth living with HIV and to ensure that they receive the highest quality care and treatment possible.

CONTEXT

444,000 people live with HIV in the Dominican Republic and while more than 20,000 people are receiving HIV treatment, many more do not have access to life-saving antiretroviral therapy (ART)¹. In 2002 the Dominican Network of People Living with HIV (REDOVIH) brought a legal challenge against the Dominican government at the Inter American Commission on Human Rights (IACHR) for breach of its duty to protect the right to life because it was failing to provide ART for all who needed it. Since then, the Dominican government has been obliged to provide an ART programme and has funded it (since 2004) through a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Despite this, there has been a lack of political will to fund the national ART programme through the State health system, and Dominican social security laws explicitly exclude AIDS medication.

Funding from the Global Fund is predicted to end in 2015 and the Dominican government is expected to assume 30 percent of the costs of these drugs by June 2013. When this project began, the government had not made any public commitments to cover the funding gap. Many HIV positive Dominicans live with the uncertainty of whether or not the government will assume these costs. Leaving people living with HIV without medication would go against the principle of universal access. Such inaction would also contradict a new HIV law introduced in the Dominican Republic in 2011, which provides for the comprehensive healthcare of people living with HIV. It would also leave the Dominican State liable to further legal challenges at the IACHR for failure to protect the right to life.

According to UNAIDS², nearly half of all annual expenditure on AIDS in the Dominican Republic is spent on care and treatment, including strengthening health systems and training service providers, yet there has been very little monitoring of the quality of care, treatment, and support received by HIV positive people. REDNAJCER has been aware for years of clinics where young people, including men who have sex with men, sex workers and tattooed people face discrimination when seeking HIV-related care and treatment. They regularly hear of

doctors bringing moralising and religious teachings into their counselling of gay or transgender clients and have seen HIV positive diagnoses being given to patients who are then chased out of the clinic.

PROJECT GOAL

To end discrimination towards vulnerabilised youth living with HIV (young men who have sex with men, young transgender people, young sex workers and young people who use drugs) in four health clinics in Santo Domingo using a community monitoring programme.

PROJECT COMPONENTS

A community monitoring programme This project was designed to put a stop to discrimination and bad practice towards vulnerabilised youth at health clinics offering HIV-related services. REDNAJCER felt that by monitoring and documenting the care and treatment services they could use the findings to pressure the government to improve its services.

As a first step, REDNAJCER socialised the project with *Dirección General de Control de las ITS's y SIDA* (DIGECITTS), the agency responsible for the government's HIV and AIDS services and national treatment programme, as well as with UNAIDS and key NGOs. This opened communication with the health sector and key decision-makers and built strategic alliances. Then REDNAJCER met with the directors of each health clinic and explained that they wanted to build partnerships with them to improve their services, an important step which encouraged the clinics not to view REDNAJCER members as enemies, but instead as allies in the health sector working with vulnerabilised groups.

REDNAJCER developed two sets of surveys, which they validated with youth and trained peers to apply. One was comprised of 18 questions directed at users of integrated HIV and AIDS services and another was comprised of 12 questions and directed at users of general services.

In total, REDNAJCER applied 159 surveys to assess a range of factors including good treatment, privacy, accessibility to care, and resolution of needs at 4 health clinics based in Santo Domingo.

Social mobilisation and lobbying REDNAJCER quickly found during the course of socialising its project with partners that the issue of a pending treatment gap required action from civil society. So under the scope of this project REDNAJCER took leadership in mobilising civil society to call for inclusion of care and treatment in the national social security plan.

With support of CVC/COIN, REDNAJCER together with 120 organisations organised the “March for a Dignified Life” which resulted in organisations from as far as the north coast of the country and Haitian border coming together to form “The National

Front for Access to Medicines from Social Security”. It called for two things, the immediate repeal of provisions which exempted ART from the social security plan, and for the State to budget and put into operation a plan for inclusion of ART into the public health system. The march was the first time in the history of the Dominican Republic that all the networks of people living with HIV and civil society came together with a common demand. Participants walked in the hot midday sun along the highways of Santo Domingo to the doorsteps of the social security headquarters where they called for less talk and more action and “Medicines Now!” Following the march, social security officials agreed to provide a response to the “National Front” within three months. REDNAJCER held weekly vigils outside the headquarters of social security reminding them of their commitment.



REDNAJCER's members have been holding weekly vigils outside of social security. Geisha's sign reads, "Respect our demands or we will see you in the Constitutional Court. We ask for respect". Photo: Fran Afonso



REDNAJ CER helped mobilise one of the Dominican Republic's largest marches yet calling for access to treatment through social security.

INITIAL RESULTS

Results of the community monitoring programme

All the participants in the survey were youth between ages 18 to 30, with just under half between ages 21 and 25. Nearly all were members of vulnerabilised groups. Half self-identified as gay, transgender or men who have sex with men, 17 percent self-identified as sex workers and 8 percent as drug users. One fourth did not self-identify in any category.

Almost half of young people attending services felt they had been discriminated against. Health services were mostly perceived to be unfriendly and discriminatory when clients were HIV positive and either transgender, gay, or a sex worker. Visibly poor or dishevelled people received the harshest treatment. While half of participants in the study self-identified as gay, transgender, or men who have sex with men, only half of the participants were identified in the clinic as such, a good indication that healthcare professionals are not trust-

ed with important information for managing their patients' health. The majority of participants felt their HIV status was maintained confidential. Only 6 participants felt insecure about privacy and one participant indicated that a nurse had breached confidentiality.

Social mobilisation and lobbying

Following the lobbying by the National Front for Access to ART, the President of the Dominican Republic committed approximately US\$ 2.7 million for ART and HIV prevention. Nearly 60 percent of that would be assigned for purchase of ART and 40 percent for buying medicines for opportunistic infections and for conducting CD4 counts. Clearly this commitment would cover only a fraction of the cost needed to purchase ART for all who need it, but the announcement is an important first step which signals government engagement on the issue. The government has also begun a cost efficiency analysis of the inclusion of ART in the public healthcare plan and has kept civil society involved in that process.

CHALLENGES

At first it was difficult for REDNAJCER to get access to the four clinics because members were perceived as a threat by staff. Patients in the waiting room of one of the clinics also refused to allow a transgender member of the monitoring team into the clinic.

REDNAJCER also found that many service users were unaware of what constitutes discrimination and were often totally unaware of their rights. Others were worried about outing their doctors' poor practice for fear of repercussions.

THE WAY AHEAD

In 2008, the Dominican Republic spent US \$31 million on HIV and AIDS. Nearly 40 percent of that was spent on care and treatment and 20 percent on ART. Nearly half of the total funds came from international donors (40 percent of that from the Global Fund) and a quarter from private funders. Only one quarter of the total budget came from public funds and one fourth of that came from a World Bank loan which the government must pay back³.

As international donors like the Global Fund spend less on HIV and AIDS and progressively require governments to assume costs, middle income countries like the Dominican Republic must begin to assign a greater percentage of their national budget to HIV and AIDS care and treatment. This is even more important as new studies show that treatment is also an effective form of prevention.

The monitoring system created by REDNAJCER for young people living with HIV is an important way to highlight where improvements need to be made to bring the quality of care and treatment up to international standards. It is also a good model for showing how civil society can work together with healthcare providers to highlight barriers to services. Prior to this project, doctors were complaining that patients were not adhering to medication, but during the course of the project they began to realise that

this was due in part to the unfriendly services and discrimination received in their clinics.

In the short term, REDNAJCER's survey results demonstrate that discrimination against HIV positive people and vulnerabilised groups is a real problem in the Dominican Republic which undermines universal access. This is unacceptable given the large proportion of investment that has been made in HIV and AIDS care and treatment services. In the longer term, more investment must be made in the Dominican Republic's weak health system. The country spends much less on healthcare than most of its middle income Latin American and Caribbean neighbours. Waiting to see a doctor an entire day is not unusual for any patient using the public health system, let alone the most vulnerable, so it is not so surprising when an HIV positive sex worker waits half a day for a CD4 count. This must change.

Meanwhile, REDNAJCER's involvement in community mobilising is a good indicator of what civil society organisations can achieve through lobbying and direct action. Organisations like REDNAJCER play a role no government or intergovernmental agency can in pressuring and holding Caribbean governments to account on their commitments to provide universal treatment, care and support. In moving forward, REDNAJCER hopes to invest more in empowering the community of young people living with HIV so they know their rights and can demand more of government services.

¹ UNAIDS (2012), *The Dominican Republic to confront its funding treatment gap*, (available at) <http://www.unaids.org/en/resources/presscentre/featurestories/2012/august/20120823dr/>

² COPRESIDA/ONUSIDA (2010) *Medición del Gasto en SIDA*, República Dominicana 2008, COPRESIDA/ONUSIDA, Santo Domingo.

³ COPRESIDA/ONUSIDA (2010)

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This series describes projects and programmes given technical and financial support by the CVC/COIN Vulnerabilised Groups Project, a sub-recipient of a Pan Caribbean Partnership against HIV and AIDS (PANCAP) grant provided by the Global Fund to Fight AIDS, Tuberculosis and Malaria. Each report aims to highlight the contribution of Caribbean civil society organisations in responding to HIV and AIDS in vulnerable populations and presents promising programmes for scale-up by Caribbean states. For more information about CVC/COIN's Vulnerabilised Groups Project visit www.focusright.org