

# ICASO Annual Report: 2017

## ICASO: until we end AIDS

### Vision & Mission

ICASO's **vision** is an end to the HIV epidemic, with strong contributions by communities in all their diversity to achieving universal access to HIV prevention, treatment, care and support, and to defending and promoting human rights.

ICASO's **mission** is to mobilize and support diverse community organizations and networks to create and sustain effective responses to HIV.

The tremendous progress made in the 35-year response to AIDS has been possible due to sustained political leadership in donor and implementer countries, a major infusion of both domestic and international resources, consensus on goals and targets, advances in clinical science and approaches to service delivery, and strong partnerships at all levels, including between people living with HIV, other affected communities, NGOs, governments, donors, researchers, UN agencies and charitable foundations.

But success in the global response has been distributed unevenly and inequitably. Despite the progress made, almost two million people continue to be diagnosed with HIV every year and nearly a million people die of AIDS.

Around 25% of all people living with HIV still do not know they are infected. And almost half of all people living with HIV globally are not receiving treatment. HIV prevalence among key populations in most countries is alarmingly high, as is incidence among adolescent girls and young women in East and Southern Africa.

The work to ensure that communities affected by HIV have their voices heard and their rights protected is unfinished and ongoing.

That is why, after more than 25 years since our founding, ICASO remains dedicated to the fundamental platform it was founded on: advocacy for human rights and gender equality, holding governments and international institutions accountable for responding to the HIV epidemic, and promoting community sector participation and community- and rights-based responses in the fight against HIV. ICASO has always been committed to advancing the principles of the greater involvement of people living with HIV (GIPA) in the AIDS response.

Based in Toronto, Canada, ICASO is a Canadian charitable organization with a global mission. With a Board of Directors representing the most affected populations and regions of the world, with staff in three continents and partners in over 50 countries, ICASO's mandate and reach are truly global.

In 2017 we welcomed two new staff and three new Board members, and said goodbye to longtime board member Don Baxter.



## Our Work in 2017

In 2017 ICASO finalized an ambitious strategic planning process, through which we consulted many of our partners around the world. We sought insights from our peers, our audiences, our funders, and our own team on what they saw as the key challenges and opportunities facing the HIV response, and ICASO itself. In mid-2017 we published our new [strategic plan for the 2017-2020](#) period. It is a reflection of what we learned, and what we hope to achieve in the near term. “Evidence, Alliances, Advocacy: Sustaining community responses to HIV,” is truly a defining moment for our organization, as it gives us a clear roadmap to tackle some very big issues, even as our organization continues to evolve, and the HIV response itself enters uncharted waters.

Because we see the strategy as foundational to all we do moving forward, this report of our activities in 2017 is structured along the strategic objectives and focus areas laid out in the strategy. While most of our work is pertinent to more than one strategic objective, activities are described here under the most relevant objective and focus area.

This report is a snapshot of the work achieved in 2017, some of which has carried over into 2018. The highlights in this report focus on examples of those activities which exemplify crossover between the three strategic objectives.



**STRATEGIC OBJECTIVE** **1 EVIDENCE**  
**FOR ADVOCACY AND ACTION**

Support initiatives to strengthen capacities and skills in the community sector to access, generate, interpret and use scientific and other forms of evidence to support advocacy, policy and programming.

**What this means in practice...**

This strategic objective focuses on strengthening the capacity of community partners to **interpret and use** available evidence (focus 1.1) and **capture community-led experiences** and knowledge (focus 1.2) – both to be used for advocacy and action.

In 2017, ICASO worked with a diverse group of advocates in different regions to support the documentation and use of knowledge, evidence and experiences to ensure our advocacy is centered on what is happening on the ground.

For example, in Zimbabwe, ICASO worked with Pangaea to document the country's unique experience in building community leadership to assist the Ministry of Health and the Global Fund Country Coordinating Mechanism in developing HIV prevention strategies for key populations. This research, which was completed in 2017, fed into a set

of recommendations for Zimbabwean civil society to continue strengthening its engagement in Global Fund and other related processes.

In Venezuela, ICASO worked with [Acción Ciudadana contra el SIDA](#) (ACCSI) to document the health crisis in the country and show how it has impacted the national AIDS response. [Triple threat: Resurging epidemics, a broken health system, and global indifference to Venezuela's crisis](#) has been shared in English and Spanish with key decision makers at national, regional and global levels to push for humanitarian help for Venezuela and more importantly to seek policy changes at The Global Fund to Fight AIDS, TB and Malaria.

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*"The shortage of antiretrovirals is being accompanied by a shortage of drugs for opportunistic infections, which also are not available in the country and end up worsening the patient's condition. The same is happening for several years, and has become more acute with the reagents for CD4 count tests (both start and follow-up) lymphocytes and viral load."*  
*Krisell Contreras, infectious disease specialist and president of the Venezuelan Society of Infectious Diseases*

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In Tunisia and Jordan, ICASO worked with Lebanon-based [Regional Arab Network Against AIDS \(RANAA\)](#) to assess the countries’ readiness to transition after Global Fund withdrawal and to achieve sustainability of HIV and harm reduction programs. The comprehensive assessments point to the need to develop transition plans in which civil society is a true partner with government. According to RANAA’s report, it was because of ICASO’s support that they were able to assess, “the consequences of the Global Fund withdrawal for HIV and harm reduction programs in Jordan by evaluating the country’s readiness and the processes for transitioning.”

One key issue that became a priority for ICASO in 2017 was the support required to get the messages behind U=U (undetectable = untransmittable) into the networks of civil society around the world. The scientific evidence is clear and unequivocal: effective treatment reduces HIV transmission risk to zero.



ICASO developed, in partnership with key leading Canadian organizations, a [community brief](#) to provide the HIV community with current information and analysis of new and updated clinical data on the effectiveness of antiretroviral therapy (ART) in preventing HIV transmission to sexual partners of people living with HIV.



HIV prevention continues to lag in the AIDS response. While UNAIDS estimates that about a quarter of the funding needed to end AIDS by 2030 should be allocated to HIV prevention, research conducted by ICASO and EANNASO shows that we are far behind that goal. The project examined funding requests and signed grant agreements from a sample of 25 African countries over the 2014-2016 funding cycle to determine how much the Global Fund is investing in HIV prevention interventions. The analysis showed that both funding requests and signed grants averaged about 15% of their budgets allocated to prevention, substantially below what is needed. The discussion paper, [A Quarter for Prevention](#), has been shared widely and was used as the basis for an intervention at the 40<sup>th</sup> UNAIDS Programme Coordinating Board Meeting.



**STRATEGIC OBJECTIVE** **2 ALLIANCES**  
**FOR DIALOGUE, EXCHANGE AND LEARNING**

Create opportunities for strategic, action-oriented dialogue, exchange and learning within the community sector and with allies in other fields of health, justice, human rights and development.

**What this means in practice...**

This strategic objective focuses on our approach to working with and supporting partners and allies all over the world to create and take advantage of opportunities for cross learning and meaningful and strategic discussion. Whereas by participating in key events and processes (focus 2.1) or by creating opportunities for exchange (focus 2.2) or by strengthening strategic alliances for cross learning (focus 2.3) ICASO is a firm believer that the work that needs to be done cannot be done in isolation and that joint strategies based on mutual trust and respect are vital for this.


A major impact center for ICASO in 2017 was the provision of technical assistance and financial support for community engagement in Global Fund funding request development, to ensure not only meaningful engagement throughout the grant lifecycle, but also that relevant and impactful interventions were included in HIV and TB prevention and treatment programs.

ICASO worked in partnership with [Réseau Accès aux Médicaments Essentiels](#) (RAME; working throughout Francophone Africa), [Eastern Africa National Networks of AIDS Service Organizations](#) (EANNASO; working throughout Anglophone Africa), Health and Rights Education Program (HREP; Malawi), [APCASO](#) (working throughout Asia-Pacific), and Gay Latino (working in Latin America and the Caribbean). In total, this work benefited partners in at least 25 countries.

In Francophone Africa, RAME provided technical support to community networks in 11 countries to more effectively engage in Global Fund processes throughout the grant lifecycle, and also developed a French-language

tool: *Orientation Guide for Civil Society Activists and Communities in Global Fund Processes.*

In Anglophone Africa, EANNASO worked in 7 countries, providing a wide variety of technical assistance. For example, in Tanzania and Ghana, EANNASO facilitated the development of a priority charter for “non-state actors,” which strengthened community engagement in the development of the Tanzania funding request. In Nigeria, a community review panel was established to consolidate priorities and monitor their inclusion throughout funding request development and grant-making. In Zanzibar, we supported the establishment of a civil society and key population task force to monitor grant implementation and facilitate community input on future Global Fund and national strategic planning processes.



In Asia-Pacific, ICASO supported APCASO to produce a compendium of case studies of past work. These case studies revealed critical lessons learned for the provision of technical assistance for community engagement across three processes: funding request development for the regional malaria elimination initiative (RAI), the establishment of the Activists Coalition on TB Asia-Pacific, and engagement with the “new funding model” in Vietnam in 2014. This research is ongoing and is expected to be completed by the end of 2018.

One of our key strategic partnerships is with the global key population networks, under the umbrella of the Free Space Process (FSP). Among its priorities, the FSP focused its work in 2017 on the Sustainable Development Goals and the High-Level Political Forum (HLPF). Our joint focus has been on ensuring the meaningful involvement of communities and key populations at national and global fora to present evidence of best practices and lessons learned and ensure that any country reports – and the resulting outcome document – takes into consideration the views and issues of our partners. ICASO has used its extensive experience in facilitating similar review and reporting process on AIDS (such as the high-level meetings on AIDS and the country-level monitoring and reporting processes led by UNAIDS) to input into the SDGs-related processes.

Two key publications were launched by ICASO to support community engagement in Global Fund processes:

1. [“How to Advocate for Community Responses and Systems Strengthening interventions in Global Fund Funding Requests”](#)

The purpose of this information note is to support civil society and community groups to design and include community systems strengthening interventions and community-based monitoring activities in funding requests during the 2017-2019 Global Fund funding cycle. The document, which was co-developed with the Global Forum on MSM & HIV, highlights the wide range of community-led interventions and systems strengthening opportunities that may be included in funding requests to increase impact against the three diseases.

### Our work in Malawi

ICASO provided support to HREP, in Malawi to enhance the meaningful engagement of civil society organizations on the Global Fund’s allocation for Malawi for the period 2017-2019. With ICASO support, HREP organized four community consultations to set priorities for key population interventions to be included in the funding request. Notably, HREP and other civil society partners in Malawi have indicated satisfaction with the community and key population components in the funding request and the final grant, which was approved in October 2017. This is one indicator of positive community impact during funding request development and grant-making. HREP also led the development of a CSO Community Charter to guide priority-setting in this and future HIV-response processes.

A key aspect of HREP’s work was also to examine and document the involvement of CSOs and explore how to ensure concrete CSO impact in funding request development and grant-making. Looking ahead, the work of HREP to-date has positioned them to act as an efficient watchdog for monitoring grant implementation beginning in 2018.

## GIPA acknowledgement for the HIV/AIDS research community

### CALL TO ACTION

If your research is about HIV and involves gathering data, lived experiences, biological samples or other aspects from the bodies or lives of people living with HIV and our participation as people living with HIV has influenced your work, we encourage you to consider and build upon the sample text provided as an acknowledgement of the role that people living with HIV have played in the response to HIV at the beginning of any presentation of your work.

We encourage you to consider an acknowledgement of people living with HIV that reflects your research and what we are providing for your consideration is three different formats and lengths for you to adapt.

#### SAMPLE FULL TEXT

*"I want to begin my presentation by thanking the people living with HIV who have generously shared their time, experiences, and bodies for the purposes of this research. Much of the fight against HIV and AIDS relies upon people living with HIV continuing to put themselves forward and this research and our fight against HIV and AIDS is indebted to those past and present."*

#### SAMPLE MODIFIED FULL TEXT

*"I want to begin my presentation by thanking the people living with HIV who have participated in this research. Our fight against HIV and AIDS is indebted to people living with HIV both past and present."*

#### SAMPLE SHORT TEXT

*"I want to begin by acknowledging and thanking the people living with HIV who have generously participated in this research."*

### RATIONALE

- Participation of people living with HIV in research has been and continues to be for the benefit of all people living with HIV across the globe.
- HIV research does not exist without the involvement of people living with HIV. The value of the lived experience is both unique and profound.
- People living with HIV are essential and equal partners in the development of effective treatments and 'HIV cure' research. People living with HIV remain vital to an effective HIV response.
- People living with HIV have and continue to willingly put our bodies on the line for science and for the benefit of the HIV/AIDS response globally.
- Because people living with HIV are diverse, there is a continual need to include the variety of lived experiences to reflect this diversity (Indigenous people, people of diverse genders and sexualities, people from numerous cultural and/or religious backgrounds, people who inject drugs, sex workers etc.).
- A meaningful acknowledgement of research subjects builds trust between researchers and affected communities.

### GOOD PRACTICE

- A statement of acknowledgement represents and supports the principles of the meaningful engagement and the greater involvement of people living with HIV (GIPA and MIPA) which has been endorsed at the highest levels and across numerous countries<sup>1</sup>.
- The UNAIDS policy brief on this matter states that we must "ensure that people living with HIV are included in the design of ethical research for new prevention technologies and the development of treatments." The brief goes on to acknowledge that PLHIV provide vital knowledge and skills towards research development and implementation as well as the necessary advocacy for a meaningful and robust research agenda.
- Ideally, people living with HIV should be involved at all stages of HIV/AIDS research from design through to analysis and publication. Involving people living with HIV in the full research process demonstrates a commitment to GIPA/MIPA and models the behavior for other researchers.
- The history of the global response to HIV has always challenged the ways in which health policy, service delivery and research is conceived and implemented. This Call to Action continues this proud history of advocacy to ensure that PLHIV are seen as central and vital to our continued fight against HIV/AIDS.



A joint initiative between Living Positive Victoria and ProAction (Australia), GNP+, ICW and ICASO (December 2017)

<sup>1</sup> <http://data.unaids.org/publications/2007/11/29/20071129.pdf>

illustrate a number of best practices to consider in the design and operations of a Positive Lounge at the International AIDS Conferences.

2. ["How Civil Society and Communities Can Engage in Global Fund Grant-making Processes"](#) This information note describes the steps involved in moving from a funding request to a signed grant. It recommends entry points, resources, and technical assistance available to support communities and civil society during this phase. This document was also co-developed with the Global Forum on MSM & HIV.

As another example of partnerships, in ICASO's role as permanent member of the International AIDS Conference's Coordinating Committee, we have worked with others to ensure that the conference remains accessible, both in terms of language (making relevant information available in Spanish) and participation (by ensuring a strong scholarship program). Also in this role, ICASO worked with the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW) to develop a [call to action for researchers](#) working in HIV. The call focuses on the request that any researchers presenting abstracts at International AIDS Conferences begin their presentations with a dedicated thanking and acknowledgement of the contributions of people living with HIV to their work. IAS has accepted the call to action and is working with ICASO and other partners to promote and evaluate its impact at AIDS 2018.

In this role as well, ICASO developed a best-practices guide for "Positive Lounges" at International AIDS Conferences. These are dedicated spaces for people living with HIV who attend the conferences and have been a feature of almost all the AIDS conferences. The paper gathers together the performance reports of the numerous Positive Lounges reported upon in conference evaluations as well as direct feedback from people living with HIV through social media outlets to



**Global Fund TA-Provider:  
Community, Rights and Gender  
Strategic Initiative and the  
Sustainability, transition and co-  
financing Initiative**

ICASO submitted a proposal to serve as a pre-qualified technical assistance provider as part of the Community, Rights and Gender Technical Assistance Program. We were selected to be part of the pre-qualified pool of TA providers for the 2017-2019 period.

ICASO has deep insights on most aspects of engagement with Global Fund processes, but has established itself as a leader on funding request development and grant-making.

ICASO has been accepted as a Technical Assistance provider for the Global Fund’s Sustainability, Transition, and Co-financing initiative. We applied for and have been pre-qualified to provide TA to countries and CSOs on Transition Readiness Assessments. We are one of only a few CSOs that have been pre-qualified as TA providers under this initiative.

The links between HIV and tuberculosis are undeniable. More and more, HIV advocates have become TB advocates. And in 2018, the United Nations General Assembly will host the High-Level Meeting on TB, which is expected to result in an outcome document that will pave the way for a comprehensive and effective response to TB. ICASO’s leadership and experience in similar processes in the AIDS response has been recognized and we have been invited to share lessons from our leading role in the AIDS HLMS, focused in particular on ensuring meaningful involvement of civil society in the processes. ICASO will continue to support TB advocates to ensure the outcome document of this high-level meeting takes into consideration the views, experiences and recommendations of those living with and affected by TB.

**International Indigenous Working Group on HIV & AIDS (IIWGHA)**

ICASO, which has two board members from indigenous communities in New Zealand, has been a staunch supporter of indigenous representation in the Global HIV movement, with special attention paid to our home country, Canada. This year we supported our board chair (Marama Pala) and Canadian indigenous activist Trevor Stratton, to attend the 16<sup>th</sup> session of the United Nations Permanent Forum on Indigenous Issues, where they delivered a [10-point statement on HIV and indigenous communities](#). Indigenous communities around the world are being devastated by HIV/AIDS and ICASO’s

commitment to continuing to support our advocates on this issue remains steadfast.



Support evidence-based advocacy to promote sustainability, accountability and impact in the HIV response in the context of the SDGs, Fast-Track targets and universal health coverage.



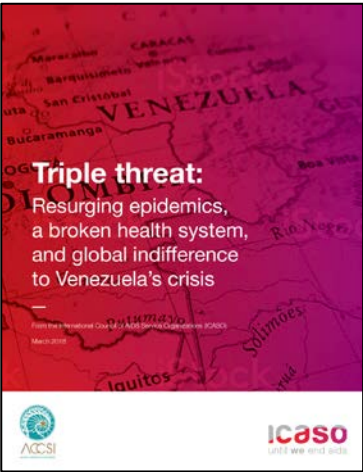


This objective has three specific focuses: the first one is looking at HIV in the context of the Sustainable Development Goals (SDGs). The second focus is looking at the sustainability of the AIDS response in an ever evolving (and reducing) funding and de-prioritization environment. Lastly, the 3<sup>rd</sup> focus is on accountability to ending AIDS.

ICASO has taken a leading role in advocating for greater donor responsibility in addressing the crisis in Venezuela. ICASO has leveraged its position in international fora to provide a platform for Venezuelan activists to be heard, such as at the IAS 2017 conference in Paris. Also, at the 40<sup>th</sup> UNAIDS PCB meeting in June, ICASO’s executive director Mary Ann Torres—herself a native of Venezuela—made an intervention to the body about the crisis. In a coordinated effort, during her remarks, others in the room stood up and held signs reading “SOS Venezuela,” in a visual demonstration of support for her plea for resources and political support. And finally, ICASO has also taken a leading role in advocating for an appropriate response from the Global Fund for Venezuela. ICASO has helped facilitate communication between key Global Fund Board delegations (Latin American and the Caribbean, Communities, and civil society) and NGOs in Venezuela, thereby applying direct political pressure to the Global Fund. In addition, ICASO presented at a roundtable in Geneva the day before the 38<sup>th</sup> Board meeting in November 2017 to highlight the Venezuelan crisis.

**What this means in practice...**  
 This strategic objective focuses on evidence-based advocacy, supported by the data collected and analyzed under strategic objective 1 with our partners and allies under strategic objective 2.

A major feature of our Venezuela advocacy this year was the publication, in partnership with ACCSI, of [“Triple threat: Resurging epidemics, a broken health system, and global indifference to Venezuela’s crisis.”](#) This report provides an overview of the crisis in Venezuela and describes the resultant public health disaster while delivering an urgent demand for different stakeholders to intervene.



Sustainability of the AIDS response continues to be a topic of great interest and controversy and although many successes of the global response to HIV/AIDS references the work that numerous communities continue to do around the world, the ongoing sustainability of the community response is always at risk.

In 2016 ICASO developed a tool for measuring sustainability of HIV responses. In 2017 the tool was used in Panama and Paraguay in partnership with the Latin American Network of Sex Workers (RedTraSex). Overall, **Civil Society Sustainability Index for an Effective HIV Response (SusX)** provided a good framework for a rapid analysis of the question of sustainability and a civil society response to HIV in the case of sex workers. Further work in this area will be undertaken in 2018.

## Looking Ahead

As we look forward to 2018, it is critical to highlight the role of communities in increasing the reach and impact of the HIV response. Continued community support for health from the perspective of HIV and human rights provides a strong base from which to connect and articulate the needs of communities and their ability to mobilize resources through their own unique cultural lenses and language. It means that their voices form an integral part of the processes of policy and decision making. It goes hand in hand with our goal of making progress towards the goals of universal access to health care and realizing the rights of everyone to achieve the highest attainable standards of health. To get there, we will need strong and engaged civil society and community participation, to propel the movement forward. In 2018, ICASO will continue to strive to support community advocates to document, advocate and address the significant gaps that remain in the response – for people, for strategies, for regions. This has been our journey for more than 25 years now, and our commitment holds: *until we end AIDS*.

We cannot end AIDS by ourselves, not introspectively, not within our silos, and not within our movements. We absolutely cannot leave anybody outside or behind in our efforts. Ending AIDS requires bold thinking, brave efforts, transformative approaches, and above all, trust among ourselves.

**Together we can end AIDS.**



**icaso**  
until we end aids