

# Evidence, Alliances, Advocacy:

Sustaining community responses to HIV

**STRATEGIC PLAN 2017-2020**

**icaso**  
until we end aids



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# Foreword

For nearly 30 years, ICASO has played a vital role as the community voice in the global fight against HIV and AIDS. At a time when governments, researchers, donors and the United Nations system were only beginning to understand the magnitude of the challenges posed by this global epidemic, our founders fought for a place at the table. They were often not welcomed and their presence was frequently a source of profound discomfort for the powerful. The legacy of those early activists from all corners of the world - fighting for their own lives and for the very survival of their communities - is immeasurable.

Since then, communities living with and affected by HIV have fought many battles, suffered many setbacks and achieved remarkable progress. It is through their efforts that scientists and doctors have come to treat participants in research and patients as partners, rather than passive subjects and recipients of care. It is because of the relentless advocacy of sex workers, drug users, men who have sex with men and transgender people that attention to human rights is now seen as an essential part of the response to HIV. And it is through the persistent advocacy of people living with HIV themselves that no program, service or policy is seen as truly legitimate unless it has been developed or delivered with their full participation. ICASO is proud to have played its part in these remarkable gains.

Access to antiretroviral treatment has brought renewed vitality to communities affected by HIV around the world. Even as we recognize this remarkable progress, we also know that half of the people in need of treatment still do not have access, that access to treatment for key populations is grossly inadequate, that stigma, discrimination and human rights abuses remain pervasive, and that unless we achieve a step change in prevention - especially for key populations, women and adolescents - the global goal of ending AIDS by 2030 will not be achieved.

We also recognize that the context of the global response to HIV is changing. In the era of the Sustainable Development Goals, we will need to work harder than ever to ensure that HIV remains a priority for governments, UN organizations and for the international community. We will need to develop new alliances in health and development to achieve shared goals. And it will be critical to continue to share evidence, knowledge and experience - especially from our own communities - about what works and what does not.

This strategic plan for ICASO for 2017-2020 aims to address this evolving context and these challenges. As we work with our constituency of diverse communities and our many partners to implement the plan over the next five years, I am confident that we will remain true to the spirit of ICASO's founders. We will continue to make our voices heard, even if at times it is not comfortable. We - the communities living with and affected by HIV - are still fighting for our lives.

Mary Ann Torres

Executive Director



# ICASO: Who we are

ICASO (International Council of AIDS Service Organizations) was formed prior to the 6<sup>th</sup> International AIDS Conference in Florence in 1991 to provide a community voice in strategic decision-making spaces at a time when the world was only beginning to come together to respond to the growing AIDS crisis. Originally conceived as a network of regional networks, ICASO has been strongly focused from its beginning 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 also been strongly committed to advancing the principles of the greater involvement of people living with HIV (GIPA) in the AIDS response.

More than 25 years later, these issues remain as important to ICASO - and to the global HIV response - as ever. At the same time, as the number of global organizations and networks representing the perspective of key populations\* and communities affected by HIV has grown, ICASO's role has evolved. As part of this evolution, ICASO adopted a global governance structure in 2012 that is independent of regional networks, under which Board members are appointed following an open call for nominations. To the extent possible, membership of the Board reflects an appropriate gender and regional balance and strong participation by people living with HIV, women and key populations, including sex workers, people who use drugs, men who have sex with men, youth and indigenous people. Two Board seats are specifically allocated to people living with HIV. Board members act in a personal capacity but have links to a wide range of local, national and global partner organizations. ICASO has the legal status of a Canadian not-for-profit organization, with a small, dynamic office based in Toronto.

This strategic plan for ICASO for the period 2017-2020 was developed through a consultative process led by the ICASO Board in 2016, including a historical review and a current situational analysis, key stakeholder interviews and Board review of drafts of the plan. The Board endorsed the plan in April 2017.

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\* Key populations in the HIV epidemic include people living with HIV, people who use drugs, sex workers, transgender people, men who have sex with men, indigenous people, prisoners, migrants, as well as women and young people.



# The changing context of the HIV response

## Progress and unfinished business

Remarkable gains in the global response to HIV have been made since the early 2000s, particularly in providing antiretroviral therapy (ART) to more than 19 million people in low- and middle-income countries as of 2016.<sup>1</sup> This progress has been made possible due to sustained political leadership in both donor and implementing countries, a major infusion of both domestic and international resources, consensus around clear goals and targets, advances in clinical science and approaches to service delivery, and strong partnerships at all levels, including between people living with HIV, affected communities, non-government organizations, governments, donors, researchers, UN agencies and charitable foundations.

Despite the progress made, around two million people continue to be infected with HIV every year and more than a million people die of AIDS. Success in the global response is distributed unevenly and inequitably. Around 40% all people living with HIV still do not know they are infected, and around half of people living with HIV globally are not receiving treatment.<sup>2</sup> 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. As people with HIV on treatment live longer, co-infections, mental health, substance use and non-communicable diseases are of growing concern. And after 30 years of the response, people living with HIV and key populations still experience neglect, stigma, discrimination, criminalization, violence and human rights violations simply because of who they are. The work to ensure that communities affected by HIV have their voices heard and their rights protected is unfinished.

## An evolving development and financing landscape

By 2017, the global response to HIV - and the international health and development landscape more broadly - had undergone significant change. The Sustainable Development Goals (SDGs) represent a paradox for the HIV response.<sup>3</sup> On the one hand, HIV has become just one among many competing health priorities for the international community to address. On the other, the SDGs establish the highly ambitious goal of ending AIDS (as well as TB and malaria) as a major public health threat by 2030. This goal is accompanied by the ambitious

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**1** UNAIDS, 2017. Global AIDS update.

**2** Ibid.

**3** United Nations General Assembly, A/RES/70/1, Transforming our world: the 2030 Agenda for Sustainable Development (October 2015).

targets set by the Joint United Nations Programme on HIV/AIDS (UNAIDS) to fast-track the global response and achieve the 90-90-90 targets by 2020, together with major reductions in new infections and the elimination of discrimination.<sup>4,5</sup>

Achieving the Fast-Track targets will require over \$26 billion for the HIV response in 2020, decreasing to around \$22 billion by 2030.<sup>6</sup> Achieving these funding targets will be challenging. In 2016, international donor funding for HIV declined for the second year in a row, falling to lowest level since 2010. Competing demands and ongoing fiscal austerity in some donor countries, have triggered increased urgency for higher domestic contributions. Donors to the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), and leading United Nations programs and agencies such as UNAIDS and the World Health Organization (WHO) increasingly emphasize the need to achieve efficiencies in the HIV response and to optimize the impact of health investments across the SDGs. At the same time, sustained political commitment to the HIV response on the part of some major donor countries is uncertain. Given the finite resources available, HIV investment cases and approaches in countries tend to favour biomedical interventions rather than community-based responses, capacity building and efforts to address structural barriers to accessing services, for which the evidence base remains less developed. Funding for technical agencies - including UNAIDS and its cosponsors - has decreased substantially, leading to concerns about the sustainability of the important role that these agencies play.

The long-term sustainability of national HIV programs is increasingly linked to the availability of domestic resources. While national governments in some countries have increased domestic financial commitments, many low-income, high disease burden countries will remain dependent on external funding for the foreseeable future, highlighting the critical importance of sustained donor support. At the same time, many middle-income countries - where 70% of people with HIV live - are faced with donors withdrawing their funding. In the context of these transitions, many governments are unable or unwilling to fund comprehensive responses, including appropriate interventions for key populations. In this context, continued vigilance and advocacy will be essential in the coming years to ensure that international donors and national governments adequately prioritize HIV and related programming, fund the interventions that are needed to achieve impact and are held accountable for results.

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**4** The Fast-Track targets stipulate that by 2020, the 90-90-90 treatment targets will be achieved and there will be fewer than 500,000 new infections among adults and zero discrimination. 90-90-90 means that 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have viral suppression.

**5** UNAIDS, 2016. Fast-track update on investments needed in the AIDS response.

**6** Ibid.



# Opportunities and challenges for the community HIV sector

## Sustainability

Adequately resourced and capacitated community-based responses are critical to ensuring the effectiveness and sustainability of the HIV response and to achieving ambitious targets in the coming years. Despite some encouraging developments, such as the creation of the Robert Carr civil society Networks Fund (RCNF) in July 2012 and increased attention to community, human rights and gender issues in Global Fund grants, funding and implementation capacity for community-driven responses to HIV remain far from adequate. In the context of global consensus on the value of differentiated ART delivery, funding for community treatment models must increase.<sup>7</sup>

Continued effort is needed to improve and disseminate evidence to effectively make the case for funding community-driven interventions, and to ensure that communities have adequate capacity to deliver and account for resources and results. Communities also need to make the case that - in addition to financing - a range of other factors negatively affect the sustainability of the response, including laws that criminalize key populations, abusive law enforcement practices, stigma, discrimination, gender inequality and other barriers to access.

## Maintaining voice and focus

Representation of the HIV community sector at the global level is more extensive than ever before. In addition to longstanding global networks such as ICASO, the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW), global key population networks representing people who use drugs, sex workers, transgender people, men who have sex with men and indigenous populations now also play a prominent role. The Global Fund has recently supported the creation of regional platforms for communication and coordination, which are playing a key role in brokering technical assistance for the meaningful engagement of civil society and community groups. Many community networks and organizations also exist at regional and national levels. While the scale and diversity of the community HIV sector are great strengths, heavy demands

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<sup>7</sup> WHO, 2016. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Recommendations for a public health approach. Second edition.

are placed on it to contribute to service delivery, technical and policy work, advocacy and governance, all within an increasingly complex global health architecture. Nevertheless, the space available for community organizations to organize, advocate and deliver services is shrinking in some countries. In others, communities battle apathy and the sentiment that because treatment is effective, AIDS is no longer a major public health issue, even though HIV prevention remains a major challenge.

To ensure that HIV remains a priority on the global health and development agenda, the voice of the community sector must be strengthened. To maintain that voice, communities will need sustained support and opportunities to meet, coordinate, strategize, prioritize, build consensus, cultivate partners and plan for action.

## Advancing innovation and learning

Innovation has been a consistent hallmark of the response to HIV, and recent advances in technology and approaches to service delivery are providing important new opportunities to increase the impact of HIV prevention and treatment, including for key populations. Such innovations include self-testing, pre-exposure prophylaxis (PrEP), treatment as prevention (TaSP) and models of care that place greater emphasis on community support for people taking ART. At the same time, the evidence base supporting the need for harm reduction, human rights-based interventions and approaches to ensuring gender equality continues to grow. Effective use and uptake of new technologies and evidence-informed approaches requires information sharing, community consultation, education, literacy, capacity building, effective links between community-based and health facility-based services, quality assurance, analysis of the acceptability of services, and close attention to removing barriers to access.

After 36 years at the forefront of the HIV response, communities possess vast experience and knowledge, but they still require support to generate, disseminate and use evidence to guide advocacy, policy and practice.

## Effective alliances for the SDG era

SDG 3 (health and well-being) is underpinned by the principle of universal health coverage, presenting an important opportunity for the further integration of HIV-specific programming and other health and social services - including maternal, child and adolescent health, malaria, tuberculosis (TB), viral hepatitis, and sexual and reproductive health and rights - that will help to ensure the long-term sustainability and impact of the HIV response.<sup>8</sup> At the same time, experience with HIV offers important lessons for other areas of health and development, such as prevention and chronic care for non-communicable diseases, and inclusive approaches to governance.

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**8** Op. cit. No. 3

To take advantage of the opportunities presented by the SDGs, the HIV community sector needs to broaden its alliances both in health and in other areas of development to identify and address common challenges and to achieve gains across the goals, in health, gender equality, access to justice, and ensuring that societies and institutions are inclusive and accountable.



## ICASO in 2017-2020: Overcoming challenges, building on our strengths

Since its founding, ICASO has played an important role in convening community processes and presenting community perspectives in major political and policy fora at the global level, including through its longstanding participation in the UNAIDS Programme Coordinating Board, its role in convening community engagement in high level meetings of the United Nations General Assembly relating to HIV, health and development, and its role as a permanent partner on the Conference Coordinating Committee of successive international AIDS conferences. ICASO is also recognized for its longstanding role in advocacy on major political and policy issues such as resource mobilization for the Global Fund, positioning the HIV response within the SDG framework, national and global accountability, the inclusion of key populations, and rights-based responses to HIV. ICASO's advocacy work has frequently been accompanied by publication and dissemination of relevant research and tools. Consultations undertaken for the development of this strategy specifically identified the following comparative advantages for ICASO:

- ICASO has a recognized ability to draw upon and take direction from a deep and diverse global network of community experts in the HIV response, especially key populations and community-based activists, implementers and policy-makers;
- A key strength of the organization is that ICASO - while remaining clear about its core mission, principles and constituency - often does not bring a predetermined position to the table, but aims to create spaces and opportunities for a wide range of community perspectives to be expressed;
- ICASO has a track record of effectively facilitating consensus and plans for action on issues of common concern within the community HIV sector and with other partners and sectors;
- ICASO is flexible and able to respond quickly to identify approaches to emerging challenges;
- In facilitating processes of consensus building, planning and problem solving, ICASO often plays an effective leadership role behind the scenes, encouraging partners to take credit and responsibility for outcomes and results.

- ICASO's advocacy focus is principally at the global level, but it is based on lessons learned from the work of regional and national community-based organizations that ICASO collaborates with.
- ICASO's location in Canada - a strong leader and voice for health and human rights - provides the organization with additional leverage at the national and international levels.

Consultations for this strategy also identified several challenges facing the organization:

- ICASO's legitimacy as a voice for the community sector in the HIV response must continue to be based on the strong skillsets and networks of its Board members, sound mission, vision and strategic goals, the quality of the work it performs to realize those goals, and the depth and diversity of its partnerships.
- ICASO's constituency now extend well beyond organizations providing "AIDS services" to a broad range of actors in the HIV community sector, including those that perform advocacy and policy development. However, if it is to remain relevant, the organization must also build alliances beyond HIV and health in areas such as social justice, education, sexual and reproductive health and sustainable development, and shape its advocacy and policy initiatives accordingly.
- At a time when progress against HIV at the country level is frequently dependent on local political and policy solutions, ICASO must work to ensure that its activities at global level ultimately contribute to progress in national and local communities affected by HIV.

This strategy for the period 2017-2020 aims to build upon ICASO's recognized strengths, while also helping to address the challenges faced by the organization and presented by the current global environment in HIV, health and development.



## Vision and 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.



# Strategic objectives

The overarching goal of this strategy is to promote strong and effective community leadership and participation on HIV and related health and development challenges, consistent with the GIPA principle, and to contribute to achieving the Fast-Track targets by 2020 and laying the foundation for achieving related SDGs by 2030. The overarching goal is supported by three strategic objectives:



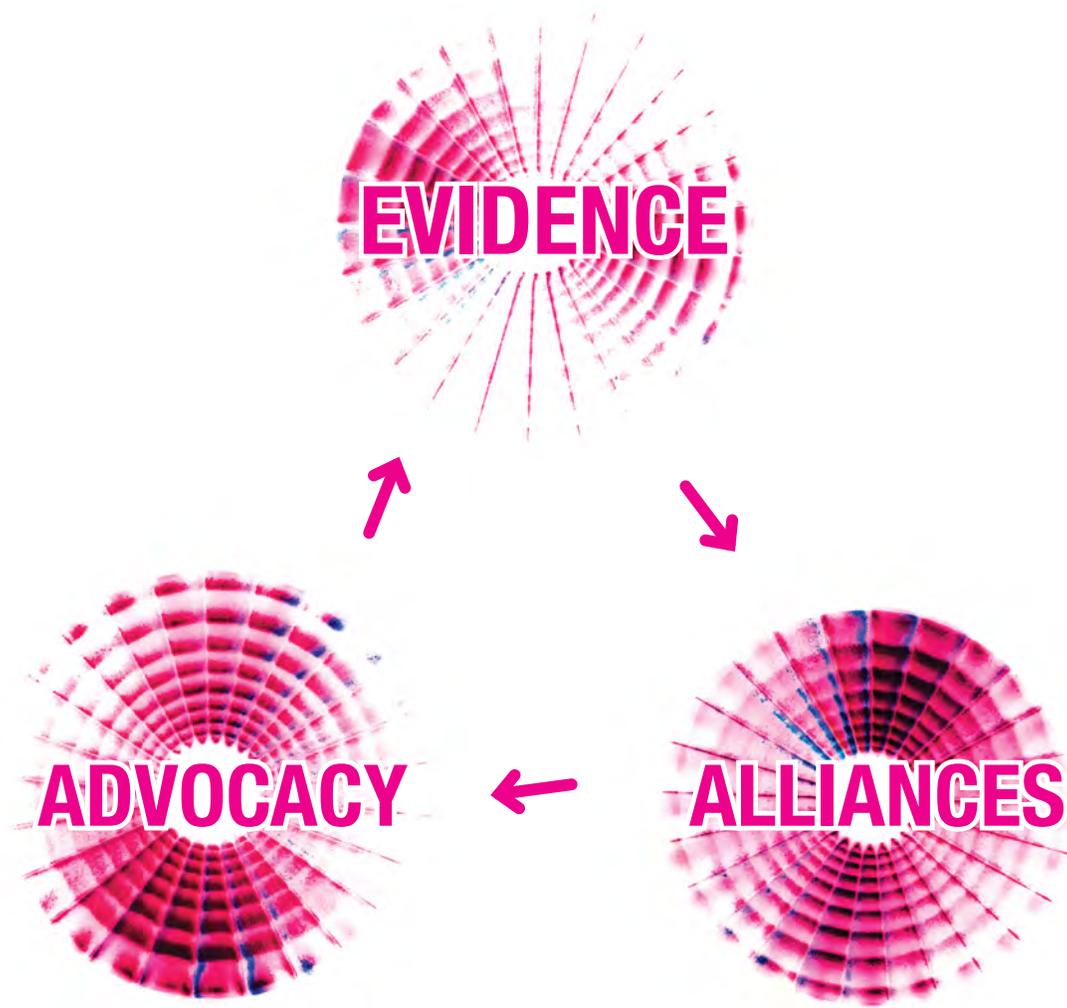
Support initiatives to strengthen capacities and skills in the community sector to access, generate, interpret and use scientific and other forms of evidence to support advocacy, policy and programming.



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.

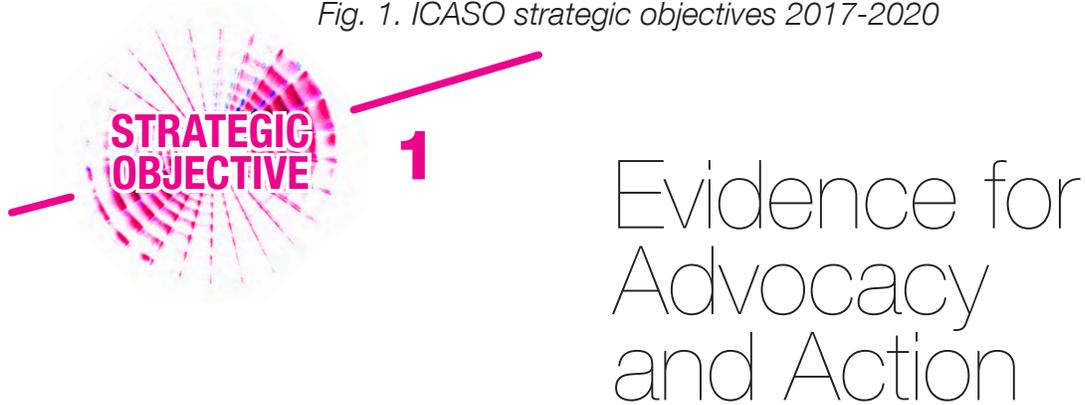


Support evidence-based advocacy to promote sustainability, accountability and impact in the HIV response in the context of the SDGs, Fast-Track targets and universal health coverage.



*Fig. 1. ICASO strategic objectives 2017-2020*

Fig. 1. ICASO strategic objectives 2017-2020



Well-funded and sustainable community responses to HIV - including the use of innovative tools and approaches - depend on a sound evidence base. More effort is needed to strengthen the capacities and skills of the community sector to access, generate, interpret and use scientific and other forms of evidence to support advocacy, policy and programming. Areas in which work is needed to strengthen the evidence base include the impact of community engagement, the most effective approaches to combination prevention, HIV testing, models of service delivery, linkages between community services and health facilities, strategies to eliminate barriers to accessing services, and finding ways to optimize synergies between HIV and related health conditions and development challenges.

ICASO's work under this strategic objective will focus on two areas:

## **FOCUS 1.1** *Strengthen community capacities and skills to access, interpret and use available scientific evidence*

-  Support initiatives to strengthen community access to scientific evidence in the HIV response, including through participation in relevant global fora;
-  Support initiatives to strengthen community capacities and skills to access, analyze and use scientific evidence in advocacy, policy and programming.



## **FOCUS 1.2**

***Strengthen capacities and skills to capture community knowledge and experience and translate it into evidence for advocacy and action***

-  Support initiatives to build the skills and capacities of community organizations and networks to generate, analyze and use their own strategic information regarding community needs and responses to HIV, including by fostering partnerships with researchers and academic institutions;
-  Support the dissemination of community-generated evidence in a range of formats, including policy briefs, case studies and advocacy tools;
-  Promote greater visibility of community-generated evidence in global scientific, policy and other relevant fora;
-  Identify and disseminate best practices and lessons learned from the generation and use of evidence by the community HIV sector.



## Alliances for Exchange, Dialogue and Learning

The global AIDS movement generates a calendar of regular events that present important opportunities for dialogue and exchange between community organizations and other stakeholders in the HIV response, including high level meetings of the United Nations, the biennial international AIDS conferences and processes related to the Global Fund. The community sector requires sustained support to ensure its meaningful engagement and participation in these events and processes.

In addition, other opportunities for the community HIV sector to undertake strategic dialogue and exchange information and learning on key themes and emerging challenges in the HIV response need to be further explored, including opportunities to discuss community-generated evidence and knowledge. Content areas for strategic dialogue, exchange and learning may include: scale-up of key interventions to achieve the Fast-Track targets; addressing service gaps and barriers to access; models of service delivery; combination HIV prevention; law and human rights; achieving impact across the SDGs; and HIV and universal health coverage. New opportunities for dialogue and exchange will also promote new leadership in the community sector and help to foster new partnerships.

In the context of the SDGs, new partnerships and alliances are especially important to promote dialogue, exchange and learning between the community HIV sector and organizations and networks working on related social justice, health and development challenges.

ICASO's work under this strategic objective will focus on three areas:



### **FOCUS 2.1**

#### ***Meaningful engagement of the community HIV sector in key events and processes at global, regional and national levels***

- Support community participation and engagement in conferences, high level meetings and other relevant events at global, regional, national and local levels, and ensure that these events include and reflect the needs of people living with

HIV, key populations, youth, indigenous people, women and adolescents;

- Support community participation in Global Fund processes at regional and national levels, including stakeholder dialogue, concept note development, governance and grant implementation;
- Support the development of tools to facilitate engagement in these events and processes.



## **FOCUS 2.2**

***Provide innovative opportunities for dialogue, exchange and learning within the community HIV sector and with other stakeholders in the HIV response***

- Work with partners to convene and/or support focused strategic dialogue within the community HIV sector and with other stakeholders to analyze evidence and discuss and plan responses to key emerging issues;
- Explore new technologies for information exchange, learning, dialogue and consultation within the community sector and with partners, including innovative approaches to online learning and social media.



## **FOCUS 2.3**

***Strengthen strategic alliances for dialogue, information exchange and learning with community networks and organizations in other fields of health, justice, rights and development to address common challenges and achieve shared goals***

- Explore and strengthen strategic alliances and opportunities for dialogue, information exchange and learning with community organizations and networks beyond HIV, including those involved in TB, malaria, viral hepatitis, maternal, child and adolescent health, sexual and reproductive health and non-communicable diseases, as well as organizations and networks engaged in promoting human rights, evidence-based approaches to public health and law, gender equality, the environment, democratic governance and institutions, and poverty reduction.



# Advocacy for Sustainability, Accountability and Impact

The community sector continues to have a vital role to play in advocacy, especially in holding key stakeholders in the global HIV response - UN agencies, donors and national governments - accountable for meeting global and national commitments and targets. Advocacy is also essential to ensure that the response is adequately funded, effective and efficient, that interventions contribute to impact against the Fast-Track targets, that the global architecture of the HIV response is fit for purpose, and that civil society and key populations are meaningfully included and adequately funded.

ICASO's work under this strategic objective will focus on three areas:

## **FOCUS 3.1** *HIV in the context of the SDGs*

-  Advocate for sustained focus on HIV in the context of the SDGs, highlight the contribution of the HIV response to progress in other areas of health and development, and identify opportunities for joint action and shared gains across development goals;
-  Work with partners to develop and disseminate evidence, analyses and tools for advocacy on HIV in the context of the SDGs, including links between the HIV response and universal health coverage.



## **FOCUS 3.2**

### ***Sustainability of the global HIV response***

- Support evidence-based advocacy in key international fora, including the United Nations, World Health Assembly and international AIDS conferences, and support advocacy with major bilateral donors, including G7 and G20 countries, for sustainable financing of the global HIV response, including for bilateral programs, the Global Fund and for countries transitioning from international donor support to domestic financing;
- In addition to international and domestic financing, promote the meaningful involvement of communities and key populations, strong community capacities and systems, and legal and policy frameworks that protect human rights, as key elements of a sustainable response to HIV.



## **FOCUS 3.3**

### ***Accountability for impact towards ending AIDS***

- Support evidence-based advocacy for interventions that will achieve maximum impact against HIV, including biomedical, economic, social and structural approaches, with a strong focus on the needs of key populations, and hold international donors, governments and other responsible stakeholders to account for progress against Fast-Track targets, with a view to ending AIDS by 2030;
- Work with partners to develop and disseminate relevant evidence, analyses and tools to support advocacy at global, regional and national levels;
- Promote accountability within the community sector, including for financial resources, and help to ensure that the sector strongly exemplifies and advances the principles of tolerance, diversity, inclusion and respect for human rights.
- Support systems strengthening for health to encourage an expansion of people-centered and community-led initiatives, including initiatives to monitor the quality and comprehensiveness of services and hold donors, governments and service providers accountable.



## ICASO's Commitment to partnership

ICASO is a network of partners and the strategic objectives in this strategy will be pursued in a strong spirit of partnership with a wide range of community organizations working in HIV, health, human rights and other areas of development. Its work is strongly grounded in the GIPA principles for the meaningful involvement of people living with HIV.

ICASO also collaborates with UN agencies and with the International AIDS Society as a permanent member of the Conference Coordinating Committee of the International AIDS Conference. ICASO is also a member of the Free Space Process, a network of organizations including key population networks, HIV treatment advocates, international NGOs, and faith-based groups. ICASO also collaborates with: organizations and networks representing people living with HIV and women living with HIV; youth-led networks; networks and organizations working on human rights and sexual and reproductive health and rights (including lesbian, gay, bisexual, transgender, intersex and two-spirited (LBGTI2) groups and women's groups); indigenous peoples; development networks and advocacy groups; researchers, academic and training institutions; and media, communications and technology professionals.



