

Defining a new AIDS activist agenda for a new era

The Board of Directors of the International Council of AIDS Service Organizations (ICASO) calls on community and civil society organizations globally to drive change.

16 May 2023

On April 17-19, 2023, the Board of Directors of [ICASO](#) met in person for the first time since before the COVID-19 pandemic to take stock of the global response to HIV and, in particular, the state of community organizing in a greatly changed political, social and epidemiological environment.

As a Board, we benefit from the direct experience and insights of Board members from Africa, Asia, and the Americas, as well as ICASO's [network of partners](#) from throughout the world.

Since the beginning of the AIDS pandemic, civil society activism has always been the engine of the AIDS response, indispensable for driving the political commitment, resource allocations, and non-discriminatory legal frameworks needed to end AIDS. ICASO is thus extremely concerned about developments threatening the sustainability and safety of ongoing activism around HIV and its social determinants.

These developments include:

- shrinking civil society space in many countries due to the erosion of democratic norms and the growth of authoritarianism;
- disinformation, distrust of evidence, and the spread of organized anti-science populism, as evidenced by many political leaders' rejection of expert public health guidance during the COVID-19 pandemic, [attacks on abortion rights in the United States](#) and other countries, attacks on [LGBTQI rights, including by state legislatures in the United States](#) and by the Ugandan Parliament, which passed the draconian [2023 Anti-Homosexuality Bill](#), with similar bills lined up by parliamentarians in Ghana, Kenya, and Tanzania;

- attacks on the very notion of human rights in many countries with significant HIV epidemics, including China, Nigeria, and Russia;
- the diversion of resources away from funding community and civil society organizations to the extent that the very existence of organizations such as the [Treatment Action Campaign](#) (TAC) in South Africa are threatened, leaving civil society with far less capacity to provide vital health services, participate in policy discussions, or carry out other activities to ensure that AIDS responses are shaped by the self-defined needs of communities;
- increasing numbers of people being displaced by humanitarian emergencies;
- growing inequalities that exacerbate the vulnerability of many women, girls, migrants, and members of LGBTQI+ communities in relation to HIV as well as other health and social issues;
- the choice of donors to focus primarily on biomedical HIV interventions while providing little funding to support HIV programs in becoming more responsive to the realities of gender and sexual diversity; and
- weak leadership by donors and governments in investing in and promoting HIV treatment as prevention – including scaling up access to pre-exposure prophylaxis.

We believe that the lack of robust civil society engagement and oversight is key to explaining why the global AIDS response is faltering, particularly in terms of stagnating financial resources. AIDS is, de facto, no longer a global priority, and the consequences of this neglect are mounting.

After more than a decade of strong progress in AIDS prevention and treatment, gains have slowed since 2010, and progress has even been reversed in some settings. The world cannot afford this, particularly as the lives of millions of people living with HIV depend directly on the donor funds that pay for their medicines through programs such as PEPFAR and the Global Fund. UNAIDS needs to do much more to listen to and work with civil society and thereby to draw more attention to the current and future challenges facing communities bearing the greatest burden of HIV.

We are also concerned that after reaping massive profits from COVID-19 vaccines, big pharma once again behaves as if it is unassailable and is increasingly immune to the idea that access to medicines, vaccines, and medical technologies is a human right. This must be challenged.

AIDS is not over, and civil society organizations leading advocacy, education, community health monitoring, frontline community service delivery, human rights monitoring, and engagement with donors need more funding and longer-term partnerships, not less. A heavily biomedical response that downplays human rights and disregards community capacities invites a resurgence of HIV and AIDS as health and social systems fail and as governments expand the criminalization of behaviors that place people at higher risk of HIV.

A new activist agenda to end AIDS and advance human rights

The ICASO Board also noted that in the face of current challenges, the AIDS activist movement itself is fragmented and uncoordinated.

It is time to regroup and formulate a new agenda, one that prioritizes saving lives and fostering well-being, one that is fundamentally defined by local communities while also addressing the global factors that influence every sphere of people's lives.

It is time to build on existing alliances and create new partnerships to address intersecting health and social issues effectively.

ICASO seeks to continue partnering with other global, regional, national, and local organizations and networks to establish a platform for communities to strategize around these issues. The [International Conference on AIDS and STIs in Africa \(ICASA\)](#) in Zimbabwe in December 2023 provides one such opportunity to convene. Additional opportunities should be identified, and ICASO stands ready to help civil society and community partners rejuvenate the AIDS activist movement in ways that speak to our changing times.

Communities coming together, COMMUNITIES DRIVING CHANGE!

ICASO invites community and civil society organizations that wish to join this dialogue about a new AIDS agenda to share their views. Comments can be sent to:

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The members of the [ICASO Board of Directors](#) are Tamara Adrian, Mark Heywood, Amy Israel, Tamil Kendall, Ronald MacInnis (Chairperson), Yolanda Paul, Meena Seshu, and Yolanda Simon.