

tagline

NEWS ON THE FIGHT TO END HIV/AIDS, HEPATITIS C, AND TUBERCULOSIS

WHAT WE WANT!

The board game grid consists of a 6x5 grid of squares. The top row contains numbers 31, 33, 34, and 35. The second row contains 26, 27, 28, and 30. The third row contains 19, 21, 22, and 24. The fourth row contains 13, 15, and 18. The fifth row contains 7, 8, 10, and 5. The bottom row contains 6. The grid is populated with several icons and text boxes:

- START**: A red starburst icon in the bottom-left corner.
- STAMP OUT STIGMA**: A text box in the bottom-left square.
- CREATIVE WORKAROUND**: A text box in the fourth row, second column.
- UNCHECKED PHARMA POWER**: A text box in the fourth row, fourth column.
- ADVANCE HUMAN RIGHTS LAW**: A text box in the fifth row, fifth column.
- STRUCTURAL OPPRESSION**: A text box in the second row, fifth column.
- GOVERNMENT STALEMATE**: A text box in the top row, second column.
- END ALL PANDEMICS**: A red starburst icon in the top-right corner.

Icons include a large red ribbon, a wooden ladder, and a red starburst.

POLICY APPROACHES TO SEEMINGLY INTRACTABLE CHALLENGES: GLOBAL AND DOMESTIC ACTIVISM IN A TIME OF DIVIDED GOVERNMENT

By Lizzy Lovinger and Mark Harrington

This November's U.S. election provides an opportunity for activists to pause and assess our approach to policy. We face some unprecedented roadblocks on our path to end HIV, hepatitis C virus (HCV), and tuberculosis (TB) — and while these challenges often feel insurmountable, we must continue to engage and develop creative new ways to achieve our goals. Where else can we turn for lessons on success? Who have we not yet engaged to leverage their policymaking power? What tools remain at our disposal in spite of seemingly intractable political barriers?

Why is this moment so uniquely challenging? In Congress, partisan gridlock and ideological deterioration on the far right have chipped away at legislators' ability to govern and undermined the ability of leaders from both parties to negotiate across differences in opinion and unite around shared goals and responsibilities to voters. Decades of consensus on funding a comprehensive HIV response domestically and globally have disintegrated, fracturing the apparent and long-lived bipartisan commitment to address pandemics such as HIV. Many bills previously considered "must-pass legislation" stalled long past their deadlines,¹ and proposed funding levels for fiscal year 2025 (FY25) have been abysmally low.²

The problem doesn't just lie within Congress, however. The Supreme Court has recently made several rulings that undermine evidence-based policies and the authority of federal regulatory agencies to use science to inform policy. Federal, state, and local health departments and related agencies have come under increasing attack, limiting their ability to effectively advise and protect the public.³ Conspiracy theories about U.S. Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), and the National Institutes of Health (NIH) abound,⁴ leading many Americans to incorrectly conclude that the agencies regularly tamper with the scientific process.⁵ A number of individual human rights protections have been significantly eroded through legal challenges to federal antidiscrimination law,⁶

making groups such as women, LGBTQ communities, people of color, and migrants far more vulnerable to marginalization and abuse. Many states in the U.S. are passing legislation that removes protection for women's sexual and reproductive freedom and stigmatizes and attempts to outlaw sexual and gender minorities such as transgender people.

The global outlook is equally grim, with similar fundamentalist and fanatic efforts undermining HIV prevention and treatment across the world. In Uganda, for example, the Parliament, President Museveni, and the High Court all ratified and upheld legislation that includes the death penalty for LGBTQ people. In response, the Ugandan Human Rights Commission (UHRC) recently called for the decriminalization of homosexuality and sex work.⁷

This political dysfunction has had a devastating effect on activist campaigns to end the HIV, HCV, and TB pandemics. Within the U.S., the court ruling in *Braidwood Management v. Becerra* opened the door for employers and insurers to deny coverage for HIV pre-exposure prophylaxis (PrEP), a key tool in preventing HIV transmission.⁸ Although the federal Ending the HIV Epidemic (EHE) initiative was launched initially by the Trump Administration, House Republicans have proposed eliminating all funding for EHE in their FY25 budget.⁹ Another lifesaving federal program developed under a Republican administration, the President's Emergency Plan for AIDS Relief (PEPFAR), was targeted for conservative political attacks against abortion services (which PEPFAR does not provide) — preventing the typical five-year reauthorization of the program and instead leading to a much shorter and less stable one-year reauthorization.¹⁰ Another example of partisan gridlock limiting public health response has to do with the ongoing outbreaks of mpox (formerly monkeypox) in a number of African countries. Despite the clear need for 10 million doses of safe, effective mpox vaccines, the U.S. — like other rich nations — has provided just a trickle of the substantial resources needed to the most-affected countries.

The House also proposed eliminating all harm reduction funds for the Substance Abuse and Mental Health Services Administration (SAMHSA),¹¹ even while new HCV infections attributable to injection drug use (with nonsterile equipment) continue to top the list of reported exposures,¹² and 7 of the 10 states with the highest HCV-related death rates¹³ were under consistent Republican leadership.¹⁴ While HCV diagnosis and treatment programs¹⁵ struggle to keep up¹⁶ with the constant need for their services,¹⁷ politicians engage in inhumane and unwise budget cuts.¹⁸ TB programs do not fare well in that budget either; just as rates of new TB infections rose to their highest level in a decade,¹⁹ CDC's domestic TB program remained flat-funded in the FY25 proposal, leaving CDC-funded state and local programs understaffed and overwhelmed.

There are still some glimmers of hope. The 1/4/6x24 Campaign, launched at the 2022 International AIDS Conference in Montreal,²⁰ takes aim at the political inertia and business-as-usual approach that has hindered progress against TB in many countries. By forming a unique coalition of civil society, ministries of health, multilateral authorities, direct service providers, and affected communities, this campaign offers a novel strategy to end TB by making the best available treatments accessible to all who need them.²¹ Partners of 1/4/6x24 come together to examine the main barriers to treatment, develop advocacy messaging and tools, organize outreach and activism, hold companies and governments accountable, determine research gaps, and ultimately ensure that as many people as possible have what they need to fight TB.²²

TAG's mid-campaign report published earlier this year shows that the campaign has achieved major price reductions in the cost of key drugs bedaquiline and rifapentine and the Cepheid test for TB. Countries such as Azerbaijan, Indonesia, Kenya, Malawi, the Philippines, South Africa, Ukraine, and Zambia are each moving TB treatment into the new era with shorter, safer, and more effective regimens.²³

This kind of ingenuity in the face of steep obstacles — by proposing a new paradigm, a new set of evidence-based goals, and actions for all partners to take in a time-bound fashion — offers a useful case study in the possibilities of activism. How can these methods of gathering stakeholders, subverting stubborn power structures, and creating ambitious but achievable goals be replicated elsewhere? Some of the aforementioned challenges provide interesting examples of policymaking targets that are due for a significant change in tactics.

Decentralizing and decolonizing global health demands new investments in global and multilateral strategies led by providers and communities in low- and middle-income

countries. The current mpox epidemic in central and west Africa, like Covid-19 and HIV before it, provides strong justification for the development and implementation of vaccine and treatment manufacturing by companies in the region.

Domestically, activists are working creatively in coalitions with local and state health departments even in places where the political environment is challenging, such as in the U.S. South.

When legislative policymaking proves difficult or impossible, activists can seek out untapped funding sources and agency collaborations elsewhere. This strategy has been successful in the case of U.S. federal funding for drug-resistant TB (DR-TB) research and development (R&D). As outlined above, the House FY25 appropriations bill severely limited spending on public health — including much-needed NIH, CDC, and U.S. Agency for International Development (USAID) funds to support and expedite studies for technologies fighting antimicrobial resistance (AMR).

One research agency fared much better in that bill: the Biomedical Advanced Research and Development Authority (BARDA).²⁴ BARDA's budget was safer and more plentiful than traditional TB R&D funding sources, and it has the proven capacity to enable end-to-end product development under an ambitious timeline. This speed in particular is crucial to addressing AMR more quickly than it can further develop; in the case of DR-TB, it is vital to have new effective treatments available faster than the bacterium can develop resistance to existing treatments. Importantly, as a CDC-designated Serious Antimicrobial Resistance Threat,²⁵ DR-TB is eligible for funding under BARDA's AMR portfolio. Though it remains to be seen whether this language will be signed into law, TB activists did achieve the unprecedented interim win of having DR-TB included in BARDA's House FY25 report language mandates.²⁶

Communities can build their own social safety nets independent of policymakers that are rooted in a human rights approach and offer consumer-responsive services and protections. This has long been the case for grassroots harm reduction providers²⁷ and mobile primary care outreach services,²⁸ but this model could be expanded to housing, working, and consumer rights. For example, a housing rights organization could train small landlords on how to respect those rights — and hold them accountable for doing so — with a "tenant-friendly" certification program. Strengthening unions and their right to organize workers is another important approach. Similarly, consumer rights programs could engage public accommodations on best practices. While activists should certainly continue to fight to protect the ironclad legal protections that remain under our current regulatory system, creative alternatives can provide useful protections through

community mobilization, “name-and-shame” strategies, and creative use of local and social media platforms.

In this issue, our colleagues outline bold visions for public health, then focus more deeply on some of the critical challenges we face today and strategies to overcome them. Gisa Dang and Mike Frick look at the ongoing, long-delayed global pandemic treaty negotiations, where many of these issues are coming to a head. TAG is working with allies to seek a reinvigorated treaty that encompasses a strong human rights–based framework. De’Ashia Lee, who runs the ACT NOW: END AIDS (ANEA) Coalition, writes a searing indictment of the historical oppression and exploitation of

Black women in the U.S. health and research systems. Joelle Dountio Ofimboudem provides an update on the continuing global challenges in accessing low-cost, high-quality generic cures for HCV. Ugandan disability activists Wilson Kutamba and Richard Musisi give us an eye-opening account of the challenges disabled people in Uganda face when trying to access HIV and TB services.

Throughout the past 32 years, TAG and our allies have worked to establish frameworks of global solidarity, access, action, and impact, to save the lives of all those living with and at risk for pandemic diseases such as HIV, TB, HCV — and we’re not going back!

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A NEW PANDEMIC AGREEMENT CANNOT SUCCEED IF IT IGNORES HUMAN RIGHTS

By Mike Frick and Gisa Dang

Background

Two years into the COVID-19 pandemic, governments embarked on a journey to create a Pandemic Agreement, negotiated among member states of the World Health Organization (WHO), that would establish binding rules on how countries respond to future pandemics. The Pandemic Agreement grew out of the abject policy failures of COVID-19. Despite earlier warnings posed by SARS, Zika, Ebola, and other infectious diseases, COVID-19 caught the world by surprise. In the resulting chaos and

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confusion, governments resorted to tools — travel bans, export restrictions on essential health commodities, Big Pharma monopoly protections, and vaccine hoarding — that favored national interests over global solidarity, with devastating consequences for human life. By defaulting to protectionism, governments missed their chance to meet the moment with actions grounded in science and public health.

The decision to create a new global health treaty was historic. South African diplomat Precious Matsoso, one of the co-chairs of the International Negotiating Body (INB), the group at WHO negotiating the Pandemic Agreement, described the motivation and stakes this way: “There is clear recognition from governments that the goal of a Pandemic Agreement is to prepare the world for preventing and responding to future pandemics, built on consensus, solidarity and equity... We know that if we fail, we will be failing humanity, including all those who suffered from COVID-19, and those at risk of future pandemics.”¹ At the start, governments seemed ready to heed hard won lessons and create a new international instrument to prevent all future pandemics. If it enters into force, the Pandemic Agreement will become only the second health accord negotiated at the WHO after the 2003 Framework Convention on Tobacco Control, making this a rare opportunity to put forward a new framework for global health cooperation.

Yet after two years of fractious negotiations, governments failed to reach consensus and pass the Pandemic Agreement. In May 2024, World Health Assembly delegates missed their self-imposed deadline to finalize the text of the agreement; negotiations are now continuing until the end of the year — and possibly into 2025. Passage of the agreement foundered on deep disagreements, including on how to handle pathogen access and benefit sharing (referred to as PABS), One Health, technology transfer, and safeguards on the transparency and use of publicly funded research. Each of these topics is highly technical in its own right but also foundational to the commitments to equity, solidarity, and science that the Pandemic Agreement was meant to affirm.

The INB is shepherding the further drafting of the future agreement and has just finished a round of negotiations in September with another planned for fall 2024.² It has a difficult task ahead and must conclude its work no later than the 2025 World Health Assembly. Among the questions that remain are: How can states determine common ground now

when they haven't found it so far? And how can states set up the Pandemic Agreement to secure scientific progress for the future of all humankind? The answer, we believe, lies in existing international human rights treaties.

Health, Human Rights, and the Pandemic Agreement

One obvious way to reach consensus is to start from points of agreement and build from precedent. International human rights law offers a natural and obvious starting point. All nations have ratified at least one legally binding international human rights treaty, and the Universal Declaration of Human Rights is so widely recognized it is considered customary international law. Even the constitution of the WHO — the legal framework under which the Pandemic Agreement is being negotiated — recognizes the right to health as the organization's second

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founding principle.³ Pandemics implicate human rights as much as they threaten health. Years of analyses of the right to health have clarified that health cannot only be realized through health interventions. In fact, the right to health depends on the underlying determinants of health — that is, the social, economic, physical environment of a person as well as individual characteristics and behaviors.⁴ Much like health, these determinants themselves are also dependent on the degree of realization of human rights.

Despite this deep connection between health and human rights, the current text of the Pandemic Agreement overlooks rights almost entirely — undermining the goals of the treaty itself. Reaffirming human rights as the basis for new rulemaking in global health would make for an agreement that's stronger, more enduring, and more adaptable to future threats.

Instead, governments have allowed the visceral politics of COVID-19 to steer the negotiations. Despite sustained pushback, the negotiations took place behind closed doors;

civil society organizations were unable to participate and, in many circumstances, were even disallowed from observing the deliberations. This lack of participation — itself a human rights principle — was starkly illustrated by scenes of advocates waiting for hours in the WHO cafeteria to catch negotiators during breaks to learn about developments and to advocate for their priorities. In our view, this procedural obstruction is a symptom of the fact that human rights are no longer the dominant frame for analyzing power in global health. In place of human rights, negotiators and other stakeholders reached for terms like equity, decolonization, and health security to stake out positions. However, these keywords ring hollow in a scenario where the process itself is not invested in modeling equity or dismantling power dynamics. Some Global North states, in particular, are following negotiating lines reminiscent of the narrow self-interests that drove early COVID-19 vaccine nationalism.

The Right to Health

With the future of the Pandemic Agreement still undecided, states have a last chance to reset deliberations by refocusing on human rights obligations. The right to health has been recognized in multiple international treaties, entitling everyone to “a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.”⁵ It seems reasonable to expect that the right to health would lay the foundation for any international agreement aiming to govern future pandemics. But in the most recent draft of the Pandemic Agreement, the right to health is mentioned twice — in the preamble and the introduction — and general references to respect for international human rights law and the human rights of everyone appear as well.⁶ The draft text, however, does not build from nor reflect this commitment. Indeed, it further departs from a human rights framework by deleting references to nondiscrimination and gender equality that were included in previous drafts.

One other human right would help states break through impasse and come out the other side with an agreement that sets the stage for a better, fairer response to the next pandemic: the right to science. Or in full, the right of everyone to participate in and to enjoy the benefits of scientific progress and its applications (ICESCR Article 15).

Best Available Science

The right to science is a close companion to the right to health, not just by the nature of the interdependence and indivisibility of human rights per se.⁷ The recognition of the right to science as integral not only to COVID-19⁸ but also to tuberculosis,

HIV, mpox, and other current pandemics, should make it a cornerstone of the Pandemic Agreement. While civil society submissions to the INB have proposed specific placements for the right to science and derivative language,⁹ it is not named in the preamble nor the body of the current draft.

This is concerning: if it had not been obvious prior to April 2020, the rights to health and to science are nowhere near fulfillment. Access to medicines activists warned early that COVID-19 was not going to be the global equalizer it was named in the beginning but that instead existing inequalities would deepen according to known patterns. Perhaps the starkest examples of this were the devastating inequities in COVID-19 vaccine access that characterized 2021 and 2022. “Vaccine apartheid” showed that the benefits of science do not simply accrue to all people eventually. As philosopher of science Michela Massimi put it, “We lack transnational institutions that can regulate and govern in a systematic way the use, distribution, and consumption of scientific advancements as transnational public goods.”¹⁰

More countries should have the ability to manufacture vaccines locally — which would require transferring technology from North-to-South and managing intellectual property in ways that favor sharing knowledge over monopolizing it.

Ideally, the Pandemic Agreement would meet this need by creating the transnational rules and mechanisms for replacing the defining failures of COVID-19 with a system capable of disseminating the benefits — whether tangible things like vaccines or intangible things like knowledge — equitably from the outset. Instead, the global answer to COVID-19 vaccination was COVAX, a donation-based model that clearly failed to fulfill its goal.¹¹ One study concluded that while an estimated 41% of excess mortality was prevented in countries that had access to COVID-19 vaccination, “an additional 45% of deaths could have been averted” with a 20% COVAX coverage target and “an additional 111% of deaths could have been averted had the 40% target set by WHO been

met by each country by the end of 2021.”¹² For the Pandemic Agreement to change the status quo of pandemic response, its provisions must move beyond “scientific nationalism” and “philanthropic solidarity.”¹³ Current language in the agreement focuses instead on the same notions of *voluntariness* and *mutually agreed terms*, which signal no great departure from the COVAX model.

Many key issues in the Pandemic Agreement are linked to the distribution of science and its benefits. The disagreements around PABS, One Health, and technology transfer all boil down to the fair distribution of scientific resources. Countries that share genetic sequence data and other information on pathogens of concern should have access to the medical tools (vaccines, drugs) whose production relies on such information. More countries should have the ability to manufacture vaccines locally — which would require transferring technology from North-to-South and managing intellectual property in ways that favor sharing knowledge over monopolizing it. People who contribute to research through either taxes or direct participation in clinical trials deserve to know how much their governments pay to purchase vaccines and other health tools that result from publicly supported research.

The right to science provides a framework for addressing this underlying issue of who benefits from science. Where the pandemic reinforced existing disparities, a new Pandemic Agreement should seek to dismantle them. Rich countries, Big Pharma, and nations with established manufacturing footprints often were in a position of deciding when other countries could access lifesaving tools. This is a trickle-down vision of how science moves: from inventors and creators to everyone else. The right to science offers a different vision of science as a fundamental entitlement shared by everyone by virtue of being human.

Commitments not Evasions

At the most basic level, treaties aim to articulate the roles and responsibilities of responsible parties in specific situations. In this case, the things governments should do to prevent, prepare for, and respond to pandemics. A successful Pandemic Agreement would have facilitated a subtle but important shift from operating by intentions and goals (e.g., states should help each other access vaccines) to acting in accordance with duties and obligations (e.g., states must set aside a certain percentage of the vaccines they buy to give to other countries in need on fair and favorable terms). This shift from imprecise aspirations toward well-defined obligations would have been more successful with stronger references to human rights given the clarity with which human rights law defines states

as duty bearers charged with respecting, protecting, and fulfilling rights.

Instead, the Pandemic Agreement text is riddled with language that tries to move in reverse by weakening new obligations as soon as they are expressed. Linguistic caveats, carve outs, and exceptions — “taking in account,” “as appropriate,” “in accordance with national laws,” “subject to the availability of resources” — puncture holes in most provisions throughout the draft. Examples are too numerous to enumerate. One provision in Article 14, which addresses regulatory systems, is almost entirely written in this evasive style (highlighting added, the brackets indicate text edits proposed by different member states that were still being decided at the moment of writing):

14.4: “Each party **shall endeavor to, subject to applicable national and/or domestic law**, adopt, where needed, regulatory reliance mechanisms in its national and, **where appropriate**, regional regulatory frameworks [for use during pandemic emergencies] [, **subject to the availability** of regulatory dossiers], [for pandemic-related health products] **taking into account relevant guidelines.**”

The proliferation of qualifying language represents an effort to reach consensus on text without really intending to change behavior. Behind such equivocating language, negotiators remain at an impasse. For example, the UK has opposed vaccine sharing requirements, whereas the Africa negotiating block is asking for a minimum of 20% of vaccines to be donated in real time to the WHO for distribution.¹⁴ Familiar factions in global health — the Global North protecting Big Pharma versus Global South advocating for technology sharing and equitable access — have reestablished themselves in the one endeavor that was supposed to break through this old dynamic.

Progressive Realization

Additional human rights references could have a positive discursive effect on the agreement text. Instead of hiding behind “as appropriate,” “where relevant,” and other similar phrases, states could fall back on the precedent of human rights language to express certain ideas more directly. This would be especially helpful in parts of the Pandemic Agreement that allow states an out by making certain actions “subject to the availability of resources.”

Major Milestones in the Development of the Right to Science

May 1948	Article XIII of the American Declaration of the Rights and Duties of Man contains the earliest expression of what will become the right to science.
December 1948	Article 27 of the Universal Declaration of Human Rights enshrines the right “to share in scientific advancement and its benefits.”
December 1966	Article 15 of the International Covenant on Economic, Social and Cultural Rights elaborates on the scope and nature of state obligations under the right to science.
July 2009	United Nations Educational, Scientific and Cultural Organization convenes series of expert meetings “to further elucidate the normative content of the right to enjoy the benefits of scientific progress,” culminating in the Venice Statement.
May 2012	Special Rapporteur in the field of cultural rights Farida Shaheed delivers the first report on the right to science to the United Nations Human Rights Council.
April 2020	Committee on Economic, Social and Cultural Rights (CESCR) publishes General Comment No. 25 on the right to science, providing an authoritative interpretation of its scope and normative content.
September 2023	Political declaration of the United Nations High-Level Meeting on Tuberculosis passes with first direct mention of the right to science in a health declaration negotiated among WHO member states.
March 2024	Special Rapporteur in the field of cultural rights Alexandra Xanthaki delivers report on the right to science and participation to the United Nations Human Rights Council.
September 2024	Political declaration of the United Nations High-Level Meeting on Antimicrobial Resistance passes with direct mention of the right to science.

Pandemic Agreement negotiators are right to acknowledge that countries are at different levels of development and therefore commitments should “[recognize] different levels of capacities and capabilities” (para. 5). But limited resources are not an excuse to not act. Human rights law acknowledges resource limitations among states in a way that preserves accountability by not letting governments off the hook entirely. This concept is known as “progressive realization.” In situations where resource constraints limit the ability of states to fully guarantee economic, social, and cultural rights, they must show they are using the resources they do have to make continual forward progress. At the same time,

this means that retrogressive action or backward progress on human rights is not justifiable. States digging their heels into positions that stand counter to human rights, therefore, does not fulfill their obligations under progressive realization.

Moreover, human rights law recognizes that some elements are so essential for the realization of certain rights that their fulfillment cannot be deferred by appeal to resource limitations; these are so-called minimum core obligations. Nearly all the core obligations under the right to science apply to pandemics. Among them is an obligation to “Ensure access to those applications of scientific progress that are critical to the enjoyment of the right to health and other economic, social, and cultural rights.” The Pandemic Agreement would be stronger if it borrowed from the idea of progressive realization to define a set of minimum core obligations that all states must honor.

Conclusion

States need to overcome their current reservations against Pandemic Agreement clauses that will require them to act in a way consistent with human rights — the right to health, the right to science, the right to participation, among others — once the next pandemic strikes. In fact, the current resurgence of mpox is already playing out in a similar pattern as COVID-19.

Endnotes

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FROM PROPERTY TO POWER: CONFRONTING THE HISTORIC ROOTS OF BLACK WOMEN'S HEALTH DISPARITIES

By De'Asia Lee

Among women aged 24–35, Black women were the only U.S. demographic for which HIV disease was a leading cause of death in 2021.¹ This alarming health disparity is the end result of a culture of oppression and devaluation of Black women that has persisted since slavery. Throughout history, Black female bodies have been exploited and stigmatized in the name of scientific and medical advancement. From the invasive gynecological experiments on enslaved women by J. Marion Sims to the utilization of Henrietta Lacks's cells without her consent, Black women have been pivotal yet involuntary contributors to key medical breakthroughs. This history of exploitation has contributed to significant and ongoing health disparities, with Black women experiencing high HIV and maternal mortality today.

Black women face systemic barriers to accessing quality healthcare, including biases within the medical community. Their mistrust of the healthcare system, especially as it relates to reproductive and sexual health, emerges from these biases, which are deeply rooted in historical exploitation. Historically, when Black women have engaged with sexual and reproductive healthcare, they have experienced an institution that devalues their right to reproductive justice and informed consent. Black women have been tortured to perfect surgical procedures, went untreated for syphilis, were unknowingly sterilized, and have had their genetic material stolen and used to achieve some of the greatest medical advances known to humanity — without attribution or financial compensation.

Anti-Black racism and sexism, which concurrently impact Black women, are as woven into healthcare as the two snakes are woven into the caduceus of the healthcare crest. J. Marion Sims is often considered the "Father of Gynecology" for his work on discovering a surgical cure for vesicovaginal fistula, a complication of childbirth that causes the vagina to continuously leak urine. Sims perfected this surgical technique by operating on nonconsenting, enslaved African cisgender

women — without anesthesia. Many of these women underwent repeated, torturous procedures, with some having as many as thirty operations.² The disregard for Black women's consent and the belief that Black women have a higher threshold for pain are examples of the historical artifacts of anti-Black racism that are foundational to the healthcare institution we know today.

The historical lack of consent experienced by enslaved African cisgender women is an injustice that still reverberates through generations today, manifesting in a lack of bodily autonomy that has been ingrained over centuries. This has had lasting effects on Black women's health, contributing to the sexual health disparities they experience currently, such as Black women being the only female demographic for whom HIV disease is a top ten leading cause of death³ and HIV criminalization laws targeting sex work, which disproportionately impacts Black women.⁴ The U.S. Public Health Service (USPHA) Untreated Syphilis Study at Tuskegee is another glaring example of the exploitation of Black bodies and the complete disregard for the sexual health of Black women. In the Tuskegee Study, Black men were left untreated and uninformed about syphilis so doctors could study the natural progression of an untreated syphilis infection. The wives and female partners of these men were ignored, unknowingly unprotected and untreated, and often gave birth to children with congenital syphilis.⁵ The lack of consideration for the reproductive health of these women speaks to a persistent devaluation of Black women's bodies.

A woman's right to make decisions for her body is a reproductive justice that has never truly included Black women. The sterilization of Black and other women of color was a state-sanctioned medical procedure that disproportionately targeted marginalized women in the twentieth century. It was so common in the South that it was colloquially referred to as a "Mississippi Appendectomy," a term coined by activist

The historical lack of consent experienced by enslaved African cisgender women is an injustice that still reverberates through generations today, manifesting in a lack of bodily autonomy that has been ingrained over centuries

Fannie Lou Hamer, who in 1961, was sterilized without consent after seeking treatment to remove a uterine tumor. From 1950 to 1966, Black women in North Carolina were sterilized at more than three times the rate of white women, many without their consent.

One of the most notable cases of informed consent violations involves a Black woman named Henrietta Lacks. Lacks sought treatment for cervical cancer at John Hopkins University in 1951. She died from the disease, but not before doctors took and shared samples of her tissues without consent. Her cells, which have the unique ability to survive and reproduce, have led to dozens of scientific and medical breakthroughs. Despite the immense scientific advancements made with her genetic material, it wasn't until 2023, more than seventy years later, that Henrietta Lacks's descendants reached a settlement with Thermo Fisher Scientific for the use of HeLa cells,⁶ highlighting a systemic culture in which Black women are expected to contribute to the greater good without proper acknowledgment or remuneration.

While modern reproductive justice movements advocate for the right to access healthcare and make decisions about their own bodies, Black women have historically been excluded from reproductive justice, facing significant injustices in medical disciplines related to reproductive or sexual health care. These fields, which include sexual, gynecological, and obstetric health, have often failed to provide Black women with the safety, respect, and care they deserve. Many enslaved African women relied on their knowledge of herbs to terminate pregnancies as an act of resistance and to reclaim control of their bodies. They did not trust a system that was built and operating on the exploitation of their bodies and their pain to care about their mental, physical, or emotional well-being. This is evident today in America, where it is dangerous for a Black woman to give birth.⁷ In 2021, Black women had the highest maternal mortality rate in the United States, almost three times



BLACK WOMEN AND HIV BY THE NUMBERS

#8

Among women aged 25 to 34, HIV disease is only a leading cause of death for Black women, coming in at #8.

1%

From 2018 to 2022, new diagnoses of HIV among Black women decreased by only 1 percent.

50%

Black women account for the largest share of new HIV diagnoses among women (3,523 or 50 percent in 2022) as well as the largest share of all women living with HIV.

24%

In 2022, Black women represented about one-quarter (24 percent) of new HIV diagnoses among all Black people.

Source: CDC

the rate of white women, according to the Center for Disease Control and Prevention.⁸ Amid this alarming statistic is the unaddressed anti-Black racism in healthcare, a legacy that traces back to J. Marion Sims, who intentionally taught students to minimize and ignore Black women's pain. The tendency among healthcare professionals to dismiss Black women's symptoms is rooted in historical injustices and attitudes and perpetuates systemic bias in healthcare, resulting in the health disparities we see today.

Another example of a health disparity that persists today is the lack of priority given to Black women's health in research. Much like the Tuskegee Study, which ignored the wives and female sexual partners of the Black men involved, many contemporary research studies also exclude Black cisgender women, focusing solely on men and transgender women. This exclusion has significant consequences given the higher rates of HIV morbidity and death in Black women. Pre-exposure prophylaxis (PrEP), a new kind of preventive medication first released in 2012 to prevent sexual transmission of HIV, is an example of this disparity. In the early iterations of PrEP studies, Black ciswomen were largely excluded despite the clear data highlighting the need in this demographic. As we saw in the Tuskegee Study, males are engaged by the scientific community and the healthcare system and females — who are capable of both sexual and perinatal transmissions — are largely ignored and unstudied.

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The lack of consent and bodily autonomy exists in HIV care and services and often manifests as limitations imposed on women, such as dissuading women living with HIV from breastfeeding due to concerns over transmission. These restrictions affect Black women and contribute to existing health inequities. Achieving health equity for Black women requires systemic changes, such as respecting bodily autonomy, promoting informed consent, and expanding clinical trial inclusion and access to innovative medications for HIV prevention and treatment. A step in the right direction would be universal access to the newest HIV prevention modalities, which have proven more effective than oral PrEP, as shown by the Gilead PURPOSE 1⁹ and PURPOSE 2 studies, which found lenacapavir, a twice-yearly injectable antiretroviral agent, 100 percent effective in preventing HIV in cisgender women and 96 percent effective in cisgender men, transgender men, transgender women, and gender non-binary individuals.¹⁰ If global and national partners work together to secure universal access at affordable prices to the most effective, evidence-based HIV prevention and treatment interventions, and with more research and integration of women's perspectives, these scientific achievements can help close gaps in HIV prevention and care for Black women, ensuring more autonomy and better health outcomes.

ACCESSIBLE DAAS SHOULDN'T BE DOA: DELIVERING ON THE PROMISE OF NEGOTIATED PRICE REDUCTIONS FOR HCV TREATMENT

By Joelle Dountio Ofimboudem

The hepatitis C Virus (HCV) remains one of the deadliest infectious diseases, despite the existence of an effective eight-to-twelve week cure. Still, of the 50 million people estimated to be living with HCV worldwide, 36 percent were diagnosed between 2015 and 2022, and only around 20 percent received treatment. Access to direct acting antivirals (DAAs) must be urgently expanded to save lives. In May of 2023, there appeared to be a promising development on that front: the Clinton Health Access Initiative (CHAI) and The Hepatitis Fund concluded [an agreement](#) with Viartis and Hetero, the leading World Health Organization (WHO)–prequalified generic manufacturers of sofosbuvir (SOF) and daclatasvir (DAC) — the most affordable DAAs that cure HCV within 12 weeks. Under this agreement, Viartis and Hetero committed to reducing the price to \$60 Ex Works¹ per treatment course in all low- and middle-income countries (LMICs). With these lower prices guaranteed, DAAs finally seemed within reach for people who need them most.

However, more than a year later, the agreement's impact appears limited: most LMICs continue to pay exorbitant prices for DAAs. People with HCV in Vietnam, for example, pay nearly \$1000 for SOF/DAC,² and people in the Philippines and Kyrgyzstan pay \$800 and \$874, respectively.³

Despite a clear desire on behalf of CHAI, the Hepatitis Fund, and the generic manufacturers to ensure that people with HCV access curative treatments to meet the WHO viral hepatitis elimination goals, the fact that the lower negotiated prices have yet to become a reality on the ground demonstrates the limitations of such piecemeal agreements with drug manufacturers to address the high cost of essential medicines. In addition to science and such upstream stakeholder deals, policy and activism are the necessary cornerstones for access to health technologies globally. To capitalize on the promise

of \$60 for DAAs, national health programs must scale up diagnostics and coordinate pooled procurement mechanisms. Civil society and affected communities also have a key role to play in realizing the benefits of lower prices for HCV cures.

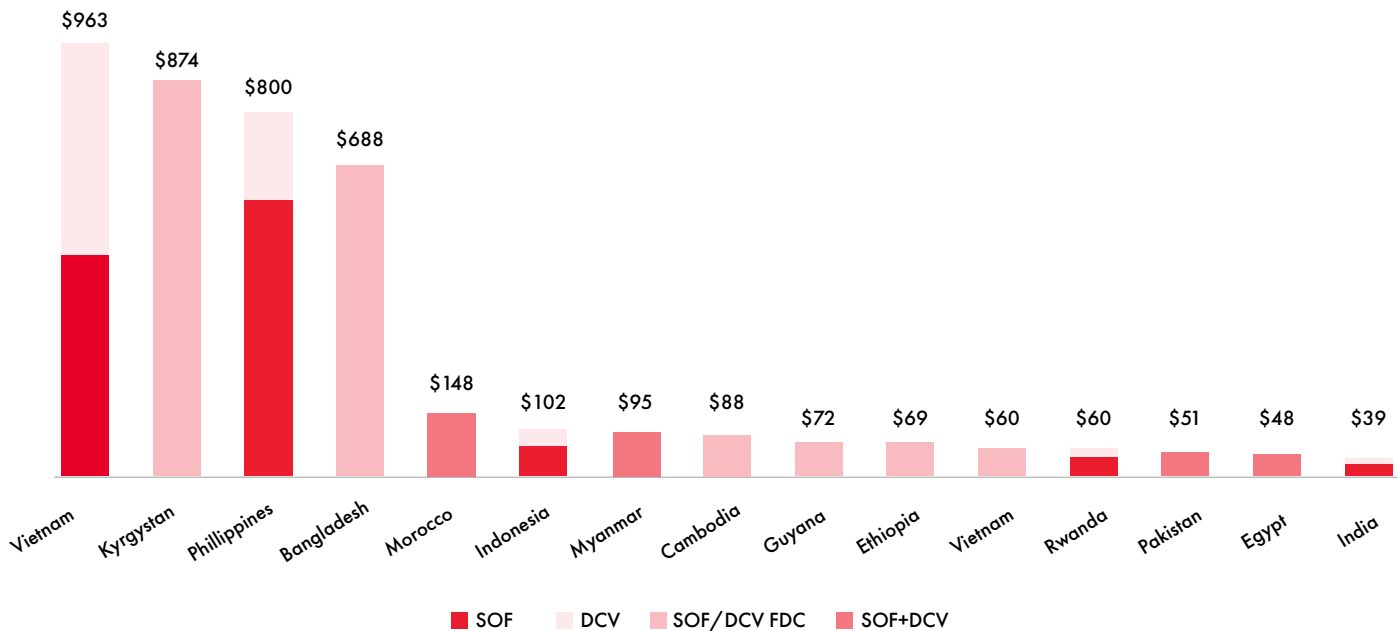
Why DAAs Remain Inaccessible Despite the Lower Prices

According to CHAI, since the deal's announcement in May 2023, countries have simply not taken up the opportunity — in fact, interest has been so minimal that the participating generics manufacturers are reportedly considering pulling out of the deal. Given the global prevalence of HCV and the high cost of treatment in most countries, this is very telling.

There are many possible reasons for governments' inaction on cheaper DAAs, such as:

- The COVID-19 pandemic caused health systems to forego other national health priorities in favor of a pandemic response, and this has not changed post-pandemic.
- Lack of routine medical care and the complicated HCV diagnostic process mean people have few opportunities to get screened and tested, so people living with HCV may only present to health facilities once they already have symptoms of serious liver damage.
- Political leaders and national health programs pay little attention to HCV (and viral hepatitis in general) and do very little to raise awareness about it, so there's no commercial demand for DAAs.
- As one HCV drug manufacturer explained in an email, "[There is a] lack of proper/timely demand forecasting. Ad hoc requests can no longer sustain

In-country Pricing Trends of SOF and DCV course for 12 Weeks Treatment Course (US\$)



CHAI HCV Market intelligence report, 2023 page 32 <https://www.clintonhealthaccess.org/report/2023-hepatitis-c-market-intelligence-report/>

this regimen ... This situation is causing critical issues to the manufacturer community because Raw Material planning goes haywire ... maintaining a manufacturing site with minimum and recurrent overheads, ensuring decent number of registrations across regions and not getting enough business is not a great situation for any manufacturer.”⁴

- Drug procurement policies in LMICs often operate in a nontransparent manner without engaging advocates or civil society, and officials may not be aware of the \$60 deal.
- Some country-level barriers to generic DAAs: in South Africa, for instance, the National Medicines Regulatory Authorities has failed to utilize the WHO Accelerated Registration process to collaborate with the WHO in the approval of generic DAC, making it impossible for generic DAC to be available in the country.⁵

Taken altogether, it shouldn't be surprising that negotiated price reductions — even if coupled with effective procurement strategies — may not result in getting cures to everyone, everywhere who need them. What we need today is a dedicated movement for global health equity more broadly and national or regional campaigns for viral hepatitis elimination that directly and strategically target and question the inequities in national and global health and international

trade, as well as intellectual property — established by the World Trade Organization Trade and Related aspects of Intellectual Property Rights Agreement — such as the Médecins Sans Frontiers Access Campaign (MSF AC) launched in 1999.⁶

The imminent closure of the MSF AC demands renewed civil society commitment to addressing the failure of the market-driven model of pharmaceutical research and development to deliver safe, affordable, and effective medicines for millions of people across the world in a timely manner. Advocates must build institutional capacity to fill the vacuum left by MSF AC, including through trainings, and community engagement, on the real barriers to access to medicines at the international, regional, and national levels among communities and civil society to enable people to understand why it is critical to mobilize and demand access to medicines. This approach, which was used by the MSF AC, allows for continuity; movement and network building across countries, regions, and globally; and knowledge exchange, enabling civil society to identify stakeholders within their communities and countries for targeted advocacy and to take action to ensure broader outcomes.

Now more than ever before, health advocates need to mobilize to build a global movement for viral hepatitis elimination to meet the 2030 viral hepatitis elimination goals. Generating

grassroots activism toward HCV elimination, as we have seen in HIV and tuberculosis, is a challenge, but it is both possible and urgently necessary. HCV elimination advocates will have their work cut out for them and must mobilize virtually and across borders to pursue a multipronged strategy to achieve a variety of demands, including:

- Pushing for the implementation of national HCV elimination plans, or the development of similar plan in countries that don't yet have them, and political leadership in HCV elimination.
- Engaging officials and the public on HCV awareness using culturally appropriate messaging for key populations before generics manufacturers pull out of the initiative.
- Leveraging existing donor funding programs and infrastructure such as PEPFAR and Global Fund to push for the integration of HCV testing, treatment and harm reduction services within these programs at the national level, and continuously making the case for the need to fund HCV and viral hepatitis elimination.
- Proposing and pushing for a coordinated and transparent pooled procurement system to achieve economies of scale.
- Emphasizing that there is an estimated return on investment of US\$2–3 for every dollar invested to prevent liver cancer deaths and increased costs of cancer treatment and care in the future, and that failing

to scale up viral hepatitis diagnosis and treatment by 2030 will drive an additional 9.5 million new cases of viral hepatitis, 2.1 million cancer cases, and 2.8 million additional deaths.

- Greater integration of HCV services into primary care and nonhealthcare settings, and expanding access to point-of-care testing to connect more people to care and limit loss to follow-up.
- Improve data and categorization of deaths driven by HCV for a more accurate and holistic picture of the virus' toll.

Finally, an effective movement to end HCV must center the social realities of communities most affected by HCV; namely, people who inject drugs, people experiencing poverty and homelessness, incarcerated populations, men who have sex with men, and more. Harm reduction and prioritizing people with HIV are key to finding and treating more people with HCV. Scaling up harm reduction services to ensure broader access to these services and safe injection use, equipping harm reduction centers to provide universal HCV screening alongside point-of-care HCV RNA testing to all people who inject drugs and ensuring coordinated and timely treatment initiation would enable many countries to regain the trajectory to HCV elimination by 2030. The considerable societal barriers these vulnerable communities face in accessing basic needs and social supports are directly related to governments' indifference toward HCV — as history shows us, movements to combat these oppressions are key to efforts to protect public health.

Endnotes

1. This is an international trade term that describes when a seller makes the goods available to the buyer at a specific location (usually the seller's warehouse or dock) and the buyer must cover all transport arrangements and costs. Ex Works pricing only encompasses the cost of producing a product. When the price of a good is set Ex Works, the buyer is responsible for other risks, such as loading them onto trucks, transferring them to a ship or plane, transport, export documentation, all freight charges, meeting customs regulations, and fulfilling the importation and delivery process.
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BREAKING BARRIERS: ENSURING ACCESS TO DISABILITY-INCLUSIVE TB AND HIV SERVICES

By Wilson Kutamba and Richard Musisi

With an estimated TB incidence of 200 cases per 100,000, Uganda is one of the 30 countries with the highest burden of TB/HIV globally. For the estimated 86,000 people living here who fell ill with TB in 2019, TB treatment coverage reached 65 percent, and the treatment success rate was 72 percent – both far below the 85 percent national target for 2019. In response, the Government of Uganda mandated the Ministry of Health, through the National Tuberculosis and Leprosy Programme (NTLP), to bring the disease under control by means of providing high-quality prevention, diagnosis, and treatment services to affected Ugandans.

Although the NTLP and other stakeholders appear dedicated to the effort to bring high quality TB and HIV services to all affected Ugandans, people with disabilities are too often left behind by such initiatives. There is a need to take bold action at national, regional, and district levels to prioritize people with disabilities and ensure they equitably benefit from all TB and HIV interventions.

The Association of Persons with Disabilities living with HIV (ADPHA Uganda, formerly known as Masaka Association of Persons with Disabilities living with HIV and AIDS) is a community-based civil society organization that advocates for the rights of persons with disabilities in the TB and HIV response. ADPHA began their operations in 2009 in the districts of Masaka, Kalungu, Lwengo, Bukomansimbi, and Rakai, eventually scaling up to include other districts, and set their sights on fighting for people with disabilities in TB/HIV programming nationwide. ADPHA Uganda is proud to be the first organized peer-support network of its kind in Uganda, with 387 current members in nine districts who are people with disabilities living with HIV, many of whom also have lived experience of TB.

ADPHA's work confirms that people with disabilities face significant obstacles in accessing TB and HIV healthcare services, despite making up 12.4 percent of Uganda's population. Their 2024 report on physical accessibility assessment of five health facilities indicated that health facilities at both district and subcounty levels are inaccessible,

lacking ramps, elevators, and accessible toilets for persons with disabilities. Furthermore, the absence of sign language interpreters at all health centers keeps people with hearing impairment away from healthcare.

Ms. Prossy Nanyombi, a person living with disability and also a peer monitor in Lwengo district, revealed that poor data-keeping can also make effective service provision difficult. Although tools do exist for data collection on disability status, health workers often don't ask for or capture this information. "Some of our members persist to make sure that their disabilities are registered but health workers rarely heed to their pleas," Nanyombi explained.

The 2024 ADPHA Uganda Accessibility Report showed still other barriers to accessing necessary TB and HIV prevention, diagnostic, and care services. Surveys found these numerous challenges are compounded by stigma and discrimination. Healthcare providers hold biases against persons with disabilities and have limited awareness of disabilities. In turn, persons with disabilities have limited knowledge about HIV and TB and lack accessible transportation, struggling to reach healthcare facilities.

People with invisible impairments like mental or hearing impairments, epilepsy, and autism face discrimination in service centers and public offices, where they may struggle to be accepted as disabled at all. "People with invisible impairments are also locked out of healthcare, as health workers only appreciate visible disabilities and rarely acknowledge/realize there are invisible ones, resulting in further exclusion in accessing public services including healthcare," explains ADPHA Program Officer Nissy Namuyomba.

According to Mr. Bbaale Mudasiru, a community leader of persons with disabilities in the Masaka district, government policies have failed to address these challenges. "There are many good laws and policies, such as inclusive education and the Building Control Act of 2013, but they are not being implemented," he explains, criticizing government officials, specifically the Office of Physical Planners, for issuing permits

for building construction without ensuring compliance with the Building Control Act 2013 and other government policies. "This reinforces limited access for people with disabilities," he notes.

Ultimately, ADPHA's accessibility report findings highlight the need for urgent action to address the barriers faced by persons with disabilities in accessing healthcare. "Government and stakeholders must work together with people with disabilities' communities to ensure that healthcare facilities are accessible and inclusive for all," the report emphasizes.

According to Mr. Joseph Walugembe, a disability inclusion specialist, expert recommendations to address these barriers include accessible infrastructure such as renovated healthcare facilities and education and training for healthcare providers on disability inclusion and awareness. In addition, community outreach is needed to build demand for health services and to understand where and how to provide accessible transportation for persons with disabilities. He notes that partners, governments, the health minister, civil society, and people with disabilities must work together to allocate resources, develop inclusive policies, support advocacy organizations, and engage people with disabilities in decision-making processes.

There are recent examples of how such stakeholder collaboration can succeed. In districts like Bukomansimbi and Rakai, where ADPHA Uganda conducted its first accessibility assessments and recommended what can be done, authorities took action by constructing accessibility ramps on toilets and other buildings at Kyetume Health Centre IV in Lwengo and added adjustable beds at Butega Health Centre IV in Bukomansimbi. Unfortunately, ADPHA advocacy can face barriers in this realm because the political will to allocate limited budgets toward accessibility doesn't always exist, according to Dr. Happy Tukrinawe of Rakai Hospital.

ADPHA has also been working with Dr. Stavia Turyahabwe, assistant commissioner health services — Tuberculosis Leprosy Control Program of the Ministry of Health, Uganda. She noted that efforts are underway to enhance inclusivity in the fight against TB, but that there is a need for all citizens to coordinate nationwide and fight tuberculosis and leprosy. "This should not be the responsibility of only health workers. We urge the public to also be part of promoting inclusivity in health among persons with disabilities and other special groups," she said.

ADPHA Uganda believes that people with disabilities themselves must play a key role in making change, and they strive to demonstrate leadership in their own communities. The association supports persons with disabilities living with

HIV and affected by TB to advocate to make changes in their lives in many ways. These include community peer support on access to HIV/TB information and services, mentoring and coaching leaders to advocate for their rights, livelihoods and emergency support, information sharing and trainings in prevention of gender-based violence and sexual reproductive health rights as stipulated in the Convention on the Rights of Persons with Disabilities.

In fact, many of ADPHA Uganda's advocacy efforts and regular trainings aim at empowering persons with disabilities to understand and assert their rights. Through continuous training from ADPHA Uganda, people with disabilities in the Masaka region have become actively involved in all government programs and have taken advantage of the available opportunities for persons with disabilities in both the government and private sectors. This includes government livelihood programs, such as the Parish Development Model, Emyooga, Youth Livelihood Fund, and the National Special Grant for Persons with Disabilities. "Although the Government of Uganda allocates 10 percent of all livelihood interventions to persons with disabilities, these grants have remained underutilized due to fear and lack of awareness among people with disabilities," explains Namuyomba. It's a policy in Uganda that 10 percent of all government programs should go to special categories including people with disabilities, elderly, youth, and women.

Finally, fighting for better healthcare for people with disabilities will require a broader social movement for people with disabilities writ large. As Juliet Nalubwama Mabike, chairperson of People with Disabilities in Kalungu and a peer monitor with ADPHA notes, apart from healthcare, even accessing education for children with disabilities is a faraway dream. "The Government of Uganda started to implement special needs and inclusive education policy five years ago where all children have to study together regardless of their disabilities. But, much like healthcare facilities, schools lack basic reasonable accommodations for children with disabilities, including assistive devices and accessible facilities, among others," she says. Uganda, like many other countries in the world, still face challenges implementing disability-inclusive frameworks and policies. Part of ADPHA's mission is to improve this.

More inclusive HIV and TB services for people with disabilities would save lives and reduce inequality. We need to build a health system that provides equitable access to quality healthcare for all regardless of age, gender, disability, or socioeconomic status and focus on the social determinants of health that keep people from getting public resources and care.

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ABOUT TAG

Treatment Action Group (TAG) is an independent, activist, and community-based research and policy think tank committed to racial, gender, and LGBTQ+ equity; social justice; and liberation, fighting to end HIV, tuberculosis (TB), and hepatitis C virus (HCV).

TAG catalyzes open collective action by affected communities, scientists, and policymakers to ensure that all people living with or impacted by HIV, TB, or HCV — especially communities of color and other marginalized communities experiencing inequities — receive life-saving prevention, diagnosis, treatment, care, and information.

We are science-based activists working to expand and accelerate vital research and effective community engagement with research and policy institutions for an end to the HIV, TB, and HCV pandemics.

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