GETTING TO THE HEART OF STIGMA

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The early days of the HIV epidemic gave rise to two epidemics: one that was viral in nature and another composed of fear, loathing and blame. Three decades into the epidemic, it remains clear:

HIV AND AIDS DOESN'T DISCRIMINATE; PEOPLE DO.

Since AIDS first appeared, we've made considerable progress in reducing new HIV infections and AIDS-related deaths. But our lack of progress in combatting the epidemic of stigma, discrimination and social exclusion undermines our efforts addressing the diagnosis of HIV, and treatment and care of people living with the virus. The persistence of stigma in the context of HIV also causes immense human hardship and diminishes us as a global community.

When we compare stigma and discrimination, stigma is often treated as a secondary matter. Although there has been a lot of lip service from international agencies to address stigma, the resources to enable an effective response to stigma at scale and duly tailored to different contexts have not been adequate. For example, global agendas for HIV prevention and treatment routinely recognize stigma as a major barrier to success. But we have yet to make fighting stigma a central pillar of our efforts in terms of allocating due resources to build a robust evidence base to enable effective anti-stigma policies and programming.

Since the beginnings of the HIV epidemic, there has been a tendency to conflate stigma and discrimination. However, while the two are related, they are also distinct. Stigma is a social phenomenon that elevates certain groups over others and steadily devalues entire groups of people.

"THE PERSISTENCE OF STIGMA IN THE CONTEXT OF HIV ALSO CAUSES IMMENSE HUMAN HARDSHIP AND DIMINISHES US AS A GLOBAL COMMUNITY."

Stigma can appear in a number of ways. Most notably, external factors can generate and reinforce stigma. These factors include: pre-existing prejudice based on gender, race, sexuality or economic position; unfounded fear of HIV. The impact of stigma can also be intensely personal and internalized: individuals may feel ashamed, dirty or afraid, withdrawing from social situations and isolating themselves from others.

Yet, looking back on the past three decades of the epidemic, hope remains: HIV also gave rise to resilience, spirit and determination. So how do we, the HIV community – people whose lives are touched by HIV professionally or personally, who are living with HIV, who are vulnerable to HIV or who know someone affected by HIV – move beyond rhetoric to action in getting to the heart of stigma?

“DISCRIMINATION IS A DIRECT ACTION THAT RESULTS FROM STIGMA.”

THE IMPLICATIONS

Sigma is multifaceted. The stigma associated with HIV itself is often compounded by other attitudes and judgments about people who use drugs, engage in sex work, have sex with members of their own sex, are indigenous, are transgender, live in poverty, have been incarcerated or have migrated from one place to another.

Discrimination is a direct action that results from stigma.

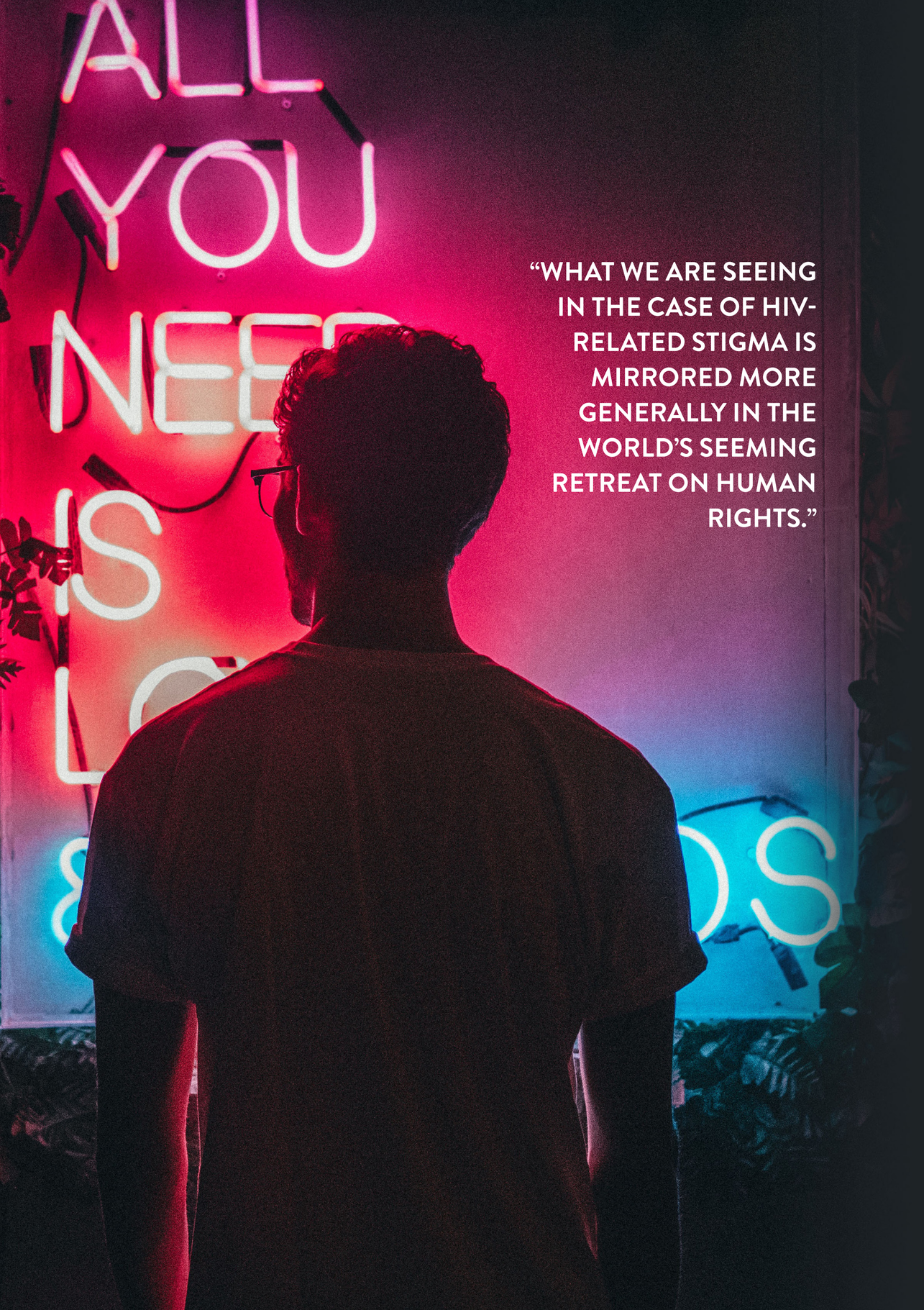
In surveys using the People Living with HIV Stigma Index in 2014-2017, unemployment was 30% or higher in 10 of the 13 counties reporting [1]. Among young people living with HIV, unemployment was 50% or more in Timor-Leste, Fiji, Greece and Honduras [1]. In countries conducting surveys in 2011-2016, 10% or more of people living with HIV reported having experienced violence as a result of their HIV status; in 16 countries, at least 10% suffered verbal harassment [2]. About one in five people living with HIV surveyed in 2012-2017 reported having been denied medical care on the basis of their HIV status [3].

Further investigation would be needed to get a fuller picture of each of these incidents as they are self-reported. Yet taken at scale, as they have been reported in the surveys, the frequency with which stigmatizing and discriminatory actions towards people living with HIV are reported highlights the degree to which stigma and fear can push people away from the services and support they need.

All forms of stigma have grave implications for the response to HIV. But perhaps none is more consequential than stigma in healthcare settings. This is why initiatives that promote best practices in healthcare settings and systematically train healthcare workers to provide stigma-free services are so crucial.

We have had some success in addressing HIV-related discrimination. According to country reports to UNAIDS, more than 70 countries have mechanisms in place for reporting and addressing human rights violations against people living with HIV and marginalized populations, although awareness of these mechanisms remains insufficient [4]. From 2011 to 2015, 22 countries or territories either removed pre-existing HIV-related restrictions on entry, stay and residence or clarified that no such restrictions were in place [5]. In recent years, Pakistan enacted legal protections for trans people [6], the Supreme Court in India invalidated the country’s legal prohibition on same-sex sexual relations [7], a law was passed in Ireland to enable licensing and regulation of supervised drug consumption facilities [8], and a movement emerged in South Africa to decriminalize sex work [9].

Yet even as progress has been made in aligning legal frameworks with human rights and public health principles, stigma persists as a major impediment in the HIV response.



“WHAT WE ARE SEEING IN THE CASE OF HIV-RELATED STIGMA IS MIRRORED MORE GENERALLY IN THE WORLD’S SEEMING RETREAT ON HUMAN RIGHTS.”

A RETREAT FROM HUMAN RIGHTS

As efforts have intensified to address discrimination, the concrete manifestations of stigma, the underlying values and attitudes that embody stigma have remained. Globally, still more than one-third of all people participating in population-based surveys in 2009-2016 said that they would not buy vegetables from a shopkeeper living with HIV [10].

The picture is especially serious for key populations – gay and other men who have sex with men, people who inject drugs, sex workers and transgender communities – in many parts of the world. We’ve recently seen mass arrests of gay men in Indonesia [11] and the forced closure of service sites tailored specifically for key populations in Tanzania [12]. Rising and continued violence against trans people is a stain on the global conscience [13]. The risk for people who inject drugs to acquire HIV is 22 times higher than for the general population [14]. In fact, since 2016, the Government of the Philippines’ concerted campaign against people who use drugs has reportedly resulted in more than 12,000 deaths [15]. Of the 195 countries in the world today, only 24 permit same-sex marriage [16]. In short, misconceived laws that criminalize people most vulnerable to HIV and people living with HIV all too frequently perpetuate a dangerous cycle of incarceration, infection and prejudice which reinforces stigma.

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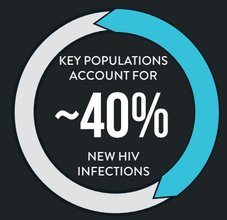

OF THE 195 COUNTRIES IN THE WORLD TODAY **ONLY 24 PERMIT SAME-SEX MARRIAGE**

Our failure to mitigate the compounded impact of stigma is unconscionable.

Stigma limits our ability to respond effectively to HIV. The evidence is clear: people who fear being stigmatized or discriminated against are less likely to seek an HIV test and to adhere to treatment [17]. What’s driving the continued expansion of the epidemic is deterring individuals from using services as a result of stigma. Young people (aged 15-24 years) account for one in three new HIV infections, and key populations and their sex partners in Western and Central Africa make up approximately 40% new HIV infections [18]. As progress towards the UNAIDS 90-90-90 targets remains off the pace towards the 2020 deadline [19], it is increasingly clear that we cannot reach these goals unless and until we address stigma, as well as the social climate and personal choices that discourage use of services.

The mistreatment of people living with or vulnerable to HIV is inconsistent with the human values to which all of us should be striving. The Sustainable Development Goals stress that no one can be left behind in our push to make the world as prosperous, equitable, healthy and just as possible by 2030. Yet when it comes to HIV, still one of the world’s most important health and development challenges, we are in fact leaving behind millions of the most vulnerable people. That is one reason why the global movement towards universal health coverage is so critical to the future of the HIV response.

Universalizing health coverage has the potential to draw more people, including members of key populations, into health services. But universal health coverage will not achieve its aims if stigma continues to deter people from accessing available health services.

What we are seeing in the case of HIV-related stigma is mirrored more generally in the world’s seeming retreat on human rights. Finding the 12th consecutive year of decline in basic democratic indicators, one leading democracy index reports that democracy currently faces its most serious crisis in decades [20]. Repression, xenophobia and authoritarianism are on the rise and the space for civil society action, free and fair elections and the rule of law are on the wane, placing our most vulnerable populations at even greater risk.

CHANGING SOCIAL NORMS

The HIV community may have had some success in preventing discrimination by enacting and enforcing laws enshrining human rights in the context of HIV – and repealing those that don't. But to combat the social phenomenon of stigma, we need a strategy that is fundamentally both social and personal in nature.

We know that various strategies work to reduce the harmful effects of stigma. For example, peer support and effectively resourcing and supporting youth-led organizations, networks of people living with HIV and organizations of key populations can aid in reaching and engaging those most affected by stigma. Likewise, strategies that effectively support individuals to overcome self-stigma and feel comfortable and confident again in themselves go a long way to promoting resilience and countering the negative impacts of stigma.

We know from the very earliest history of the HIV response that support groups and other interventions are highly effective in forging social links for people who are isolated. These are interventions that improve people's sense of self-worth, boost their confidence, build their social capital by enabling them to have a sense of belonging to a community and provide them with the information and skills they need to make healthy choices.

We also know, not only from HIV but also from a broad array of social justice issues, that social mobilization strategies can build cohesive communities and contribute to community-sensitive service delivery. Differentiated service delivery, which builds on community needs and resources, not only has the potential to sidestep the stigma and discrimination that strikes at the heart of the integrity of mainstream health facilities, but also can empower and inspire communities.

Urgent new investments are needed to bring these proven strategies to scale. Yet at their best, these strategies are primarily aimed at mitigating the most harmful consequences of stigma. What we've yet to do is apply laser-like focus on fighting stigma itself.

To be successful in responses to HIV, we must engage, challenge and change hearts and minds to remove stigma.

Where judgment, exclusion and scapegoating have prevailed, we must persuade people to act with generosity, compassion and solidarity.

Although the goal of eradicating stigma in the context of HIV appears daunting, the truth is that other movements have succeeded against similar odds in changing social norms.

The healthy eating movement, for example, is a model of how promoting positive messaging can shift behaviours and social norms without judging or devaluing people who are overweight. In the not-too-distant past, people diagnosed with cancer instinctively reacted with shame and secrecy, but in settings where diagnostic and treatment services are readily available, today cancer is widely accepted as a diagnosis without shame.

Let us model the change we want to see in our societies and in the world.

"BUT TO COMBAT THE SOCIAL PHENOMENON OF STIGMA, WE NEED A STRATEGY THAT IS FUNDAMENTALLY BOTH SOCIAL AND PERSONAL IN NATURE."

SHIFTING OUR COLLECTIVE MINDSET

The truth is that the HIV community has confronted stigma from the very beginning. Our community has been the leader in changing public perception from the early days when AIDS was wrongly assumed to affect only certain populations instead of being understood as a global epidemic. We have also often confronted our own values and approaches to question and recalibrate what we think is essential to be effective in responding to HIV.

Today, the timing is opportune to launch an urgent new effort to change public perception as scientific evidence has definitively demonstrated that people living with HIV who achieve viral suppression cannot transmit the virus to others [22].

The Prevention Access Campaign, a global health equity community, launched the Undetectable = Untransmittable (U=U) initiative, which signifies that individuals with HIV who receive antiretroviral therapy and have achieved and maintained an undetectable viral load cannot sexually transmit the virus to others. While the powerful U=U movement has resounded within the HIV community and throughout the global health field, it has yet to be embraced as a standard by the general public. Now is the time to change that. This emerging evidence thoroughly undercuts the fears that often rest at the heart of HIV stigma.

"THIS EMERGING EVIDENCE THOROUGHLY UNDERCUTS THE FEARS THAT OFTEN REST AT THE HEART OF HIV STIGMA."

A CONCRETE AGENDA

If we hope not only to minimize the effects of HIV stigma but also to eliminate stigma at its source, we'll need more than catchy slogans. We'll need to apply proven social science and community mobilization techniques to transform public perceptions and attitudes about people living with or affected by HIV. We must understand and effectively address stigma and muster the political commitment that will be required.

We must start the difficult conversations, take action when we bear witness to a stigmatizing incident, and hold ourselves to higher and more inclusive moral standards. And we'll need a renewed commitment to accountability and honesty. We must be willing to call out and directly confront those countries – as well as colleagues, family members and friends – whose actions perpetuate HIV stigma and contribute to the further spread of HIV.

To strengthen and sustain the HIV response by mitigating the negative effects of stigma, we can serve as a trailblazer for the global community. Stigma and social exclusion are at the core of many of the world's most vexing challenges. Our HIV community can show the way in resisting the temptation to treat those who are perceived as "different" as "others" who are not entitled to basic human decency and respect.

Given the multifaceted nature of stigma in the context of HIV, the HIV community will need to work hand in hand with other communities, sectors and movements. To mitigate the harmful impacts and reduce stigma, all of us will need to play our part.

- The emerging Global Partnership for Action to Eliminate all Forms of HIV-related Stigma and Discrimination is a step in the right direction (22) and it is clear that collective action is required to ensure its success.
- Governments that have codified stigmatizing attitudes will have to take immediate steps to repeal stigmatizing laws and policies, and other governments should step forward to prioritize stigma eradication in their diplomatic efforts.
- Robust mechanisms and opportunities will be needed to enable countries that continue to struggle with stigma to learn from those that have taken steps to address it.
- New funding will be needed to scale up research to build robust evidence to inform effective and context appropriate stigma mitigation initiatives
- The international global health community must sharply elevate fighting stigma to the very top of the HIV agenda.
- Healthcare workers must report incidents of stigma and ensure that their facilities are stigma-free.
- The private sector should rejuvenate its workplace programming, focusing not only on services, but also on eradicating stigma, and these programmes should be extended beyond the workplace into the communities where people live.
- People living with HIV, affected communities and broader civil society will have to have the confidence and enduring energy to continue to play their essential roles as advocates and accountability watchdogs.

The fact remains that we will never "end AIDS" until we end stigma. At this perilous moment, when the most basic of human values seem to be in retreat, the HIV community must show the world a different path.

"WE MUST START THE DIFFICULT CONVERSATIONS, TAKE ACTION WHEN WE BEAR WITNESS TO A STIGMATIZING INCIDENT, AND HOLD OURSELVES TO HIGHER AND MORE INCLUSIVE MORAL STANDARDS."

FOOTNOTES

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