THE GAP REPORT 2014

PEOPLE LIVING WITH HIV

Since the start of the AIDS epidemic, more than 78 million people have been infected with HIV and 39 million have died (1).

Acquiring HIV no longer means certain death. A person on HIV treatment in a high-income setting now has nearly the same life expectancy as a person who does not have the virus. However, only two out of five people living with HIV have access to antiretroviral therapy. Among people who do have access, great inequities exist.

People living with HIV are being left behind because they are not benefitting from health care, employment, education or social protection. This is often due to stigma, discrimination, prohibitive laws and policies or a lack of services.



I am a person living with HIV. I face these issues.



WHY PEOPLE LIVING WITH HIV ARE BEING LEFT BEHIND

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HIV burden

There are people living with HIV in all parts of the world, from all walks of life and cultures, all ages and all genders. Some are more affected than others, and some have better access to services than others.

There are 35 million people living with HIV globally.

There are 3.2 million children and 2.1 million adolescents living with HIV.

There are 4.2 million people 50 years and older living with HIV.

At the end of 2013, there were 35 million [33.2 million–37.2 million] people living with HIV globally. Seventy per cent of the people living with HIV are located in sub-Saharan Africa.

Human rights violations, stigma and discrimination

Stigma, discrimination and other human rights violations against people living with HIV limit their access to HIV services. These violations also negatively affect their ability to lead full and dignified lives (2–5).

Human rights violations affect people living with HIV in the workplace and affect their access to insurance, social security, housing and education. Sixty-eight per cent of countries have non-discrimination laws or regulations that specify protections for people living with HIV (6). Yet, in

THE TOP 4 REASONS

Human rights violations, stigma and discrimination

> 02 Access to treatment and services

03 Gender-based inequalities

> 04 Criminalization and exclusion

many contexts, stigma and discrimination towards people living with HIV still happen despite these laws. People living with HIV may experience further discrimination or a lack of legal protection because of their sexual orientation, gender identity, drug use or sex work.

Punitive laws, policies and practices increase the vulnerability of people living with HIV and affect their ability to access voluntary testing and treatment. Overly broad laws and prosecutions for HIV non-disclosure, exposure and transmission have been recorded in all regions of the world. Some 61 countries have adopted legislation that specifically allows for criminalization, while prosecutions for HIV non-disclosure, exposure and transmission have been recorded in at least 49 countries (7). 61 countries have adopted legislation that specifically allows for criminalization, while prosecutions for HIV non-disclosure, exposure and transmission have been recorded in at least 49 countries.

There are 38 countries, territories and areas with restrictions on the entry, stay or residence of people living with HIV as of July 2014 (8).

Countries with laws or recorded prosecutions for HIV non-disclosure, exposure or transmission



Laws or recorded prosecutions for HIV

Source: Global Network of People Living with HIV, HIV Justice Network. Advancing HIV justice: A progress report on achievements and challenges in global advocacy against HIV criminalization. Amsterdam / London: Global Network of People Living with HIV / HIV Justice Network; 2013.



Top 30 jurisdictions for HIV criminalization based on known arrests or prosecutions per 1000 people living with HIV and including absolute numbers of known arrests or prosecutions (data are cumulative and correct as of July 2012).

Source: Global Network of People Living with HIV, HIV Justice Network. Advancing HIV justice: A progress report on achievements and challenges in global advocacy against HIV criminalization. Amsterdam / London: Global Network of People Living with HIV / HIV Justice Network; 201.

Three decades into the response to the AIDS epidemic, people living with HIV continue to face stigma and discrimination. HIV-related stigma has damaged the social and psychological well-being of many people living with HIV. It is associated with low social support, poor physical and mental health and a poorer quality of life (5). The People Living with HIV Stigma Index shows that people living with HIV experience unemployment rates three times higher than national unemployment rates—37.7% among people living with HIV compared to average national unemployment rates of 11.7%. Reasons reported for unemployment include stigma, discrimination, restrictive policies and practices and ill health.

Evidence from the People Living with HIV Stigma Index demonstrates the significant impact of stigma and discrimination on the health and ability of people living with HIV to be active members of their community. On average, one in eight people living with HIV report being denied health services and one in nine is denied employment because of their HIV-positive status. An average of 6% reported experiencing physical assault because of their HIV status. People living with HIV who are members of key populations face a double stigma because of their sexual orientation, gender identity, drug use or engagement in sex work. Their HIV-positive status increases their risk of experiencing violence, being denied services or being excluded from community activities.

Discriminatory attitudes are common in many parts of the world. But evidence suggests that where knowledge of HIV is higher, discriminatory attitudes towards people living with HIV are lower.

Health-care providers and health professionals are sometimes the source of the stigma affecting people living with HIV. Examples include neglecting patients, providing a different quality of treatment based on one's HIV status, denying care and breaching confidentiality (4). Instances of verbal abuse by health-care staff have been reported in a number of studies (9–15).

Access to treatment and services

Voluntary HIV testing and counselling is the gateway to life-saving HIV treatment for people living with HIV, yet only half of all people living with HIV know their HIV status.

Evidence from the People Living with HIV Stigma Index shows that fear of stigma and discrimination results in delays in a person seeking an HIV test (16). This, in turn, results in the late initiation of treatment, which can result in poorer health outcomes.

For some groups, access to services is challenging, due to systemic and policy issues. For example, adolescents living with HIV face major barriers in accessing HIV testing in many countries, owing to restrictive parental consent laws and policies. Data collected from sub-Saharan Africa indicate that only 10% of young men and 15% of young women (15–24 years) were aware of their HIV status (17).

Sometimes, the way in which HIV testing is carried out violates individuals' rights. Lack of confidentiality, mandatory or forced testing among certain populations, coerced treatment initiation and mandatory disclosure of HIV status to sexual partners are violations of individual rights.

Globally, only 38% [36–40%] of adults (15 and older) living with HIV and 24% [21–26%] of children living with HIV have access to treatment.¹ As of 2013, 12.9 million people had access to antiretroviral therapy.

Access to treatment is key to halting AIDS-related deaths (18). It extends life expectancy and improves the quality of life. It is also a key to preventing and reducing morbidity. For example, evidence shows that the risk of tuberculosis declines dramatically with HIV treatment (19).

In addition to the undeniable impact of antiretroviral therapy on the lives of people living with HIV, treatment access results in a lower viral load, at individual and community levels, which in turn, reduces the potential to transmit HIV on to sexual partners (20). In other words, treatment is first and foremost to save lives. It also prevents HIV infection. Globally, only 38% of adults living with HIV have access to treatment.

¹ Starting in 2014, UNAIDS and its partners are presenting the number of people receiving antiretroviral therapy as a proportion of people living with HIV. This is done in order to avoid comparing antiretroviral therapy coverage in countries with different eligibility criteria and to avoid comparing coverage over time when the criteria have changed. This new indicator does not endorse a policy of treatment initiation regardless of CD4 cell count; it merely allows for comparisons between countries and over time. The full benefits of HIV treatment are realized when people living with HIV are given the support and care required for optimal adherence. About 86% of adults remain on treatment 12 months after initiation. While some people may move from one clinic to another, recent evidence suggests that, in southern Africa, approximately 30% of patients lost to treatment follow-up have died (*21*).

Gender-based inequalities

Women represent 50% of all adults living with HIV globally. However in the most affected region, sub-Saharan Africa, 59% of adults living with HIV are women. Almost 1000 young women are newly infected with HIV every day. Infection rates among young women are twice as high as among young men in sub-Saharan Africa.

Some women living with HIV also experience forms of institutional violence, including forced sterilization and forced abortion and the denial of voluntary sterilization or safe abortion services (22). Involuntary and coerced sterilization and abortion among women living with HIV occur in many countries. These practices have been reported in Bangladesh, Cambodia, Chile, the Dominican Republic, India, Indonesia, Kenya, Mexico, Namibia, Nepal, South Africa, the Bolivarian Republic of Venezuela, Viet Nam and Zambia, among others (23–27).

Criminalization and social exclusion

People who are socially marginalized or criminalized carry a higher burden of HIV than the general population:

- Gay men and other men who have sex with men are 19 times more likely to be living with HIV than the general population (28).
- People who inject drugs bear 28 times higher HIV prevalence than the general population (29).
- HIV prevalence among sex workers is 12 times greater than among the general population (30).
- Transgender women are 49 times more likely to be living with HIV than other adults of reproductive age (31).

The double stigma and discrimination of living with HIV and being a member of a marginalized population creates barriers to accessing services, including antiretroviral therapy, and to protecting human rights. Furthermore, politicians are not inclined to support programmes for marginalized and criminalized communities, especially during times of constrained national spending and competing public service needs. Women represent 50% of all adults living with HIV globally. However, in the most-affected region, sub-Saharan Africa, 59% of people living with HIV are women.

People who inject drugs are 28 times more likely to be living with HIV.

CLOSING THE GAP

The greater and meaningful involvement of people living with HIV in all aspects of the response to HIV leads to policies and services that are acceptable and can reach the communities they aim to reach. People living with HIV must be meaningfully involved in decision- and policy-making, programme design, implementation, monitoring and evaluation.

Earlier testing leads to earlier diagnosis and better health outcomes. Significant numbers of people living with HIV continue to present themselves for testing at a late stage, with CD4 cell counts below 200. Acceptable, accessible and affordable voluntary and confidential HIV testing with effective linkage to treatment services—whether it is at the community or health service level—results in earlier diagnosis and earlier treatment initiation, with better health outcomes.

Community-based service delivery can reach key populations where statebased facilities may not be able to. It can support health systems where capacity has been maximized and can provide services that respond to the needs of their own communities. Moreover, community-based service delivery can extend services into areas that have previously been difficult to reach.

Programmes to sensitize and reduce stigma among service providers result in increased satisfaction with services and improved outcomes. Parallel to removing systemic barriers to access, efforts are needed to put into place measures to reduce stigma and discrimination. This includes training healthcare providers, dialogue between community leaders and people living with HIV, protective workplace policies and psychosocial support.

HOW TO CLOSE THE GAP

Meaningful participation of people living with HIV

> **D** Improve services, including community-based services

Scale up antiretroviral therapy and integrated health services

O4 Increase treatment and rights awareness



Source: Zachariah et al. 2009. Task Shifting in HIV/AIDS: opportunities, challenges and proposed actions for sub-Saharan Africa. Transactions of the Royal Society of Tropical Medicine and Hygiene (2009) 103, 549–558.

Communities deliver: Malawi and South Africa

Access to life-saving antiretroviral therapy and integrated health services is essential. Affordable and accessible treatment for all—irrespective of age, sexual orientation, gender identity, religion, socioeconomic status or ethnicity—is an absolute necessity for the survival of people living with HIV. Evidence shows that people living with HIV on antiretroviral therapy can have life expectancies comparable to the general population. Continuous efforts in research and the development of better treatment and easier formulations to support adherence and retention are crucial in ensuring sustainable and quality treatment for people living with HIV.

Increasing HIV knowledge and awareness among the general population enables people to protect themselves and works to reduce stigma and discrimination against people living with HIV.

Knowledge of fundamental human rights and understanding where and how to access HIV testing and treatment are essential to removing the barriers caused by rights violations, stigma and discrimination. Literacy programmes that are community-led and delivered can reach key populations and communities, creating the necessary demand for services.



Science evolved: smarter and better HIV treatment options now available

Where the criminalization of behaviours that affect key populations exists, access to testing and treatment must not be linked to criminal prosecution or other punitive consequences. A combination of approaches is needed in order to reach a greater number of people. Confidential and voluntary HIV testing options should include clinic-based testing, mobile testing, community-based testing, door-to-door testing and home-based testing kits with linkages to clinic- or community-based confirmation testing for positive results.

Innovative testing and service delivery models include multi disease, community health campaigns and service delivery (32). New technologies such as self-testing encourage a high uptake of HIV testing (33).

Projected impact of highly active antiretroviral therapy on expected survival of a 20-year-old person living with HIV in a high-income country



Source: Adapted from Lohse et al, 2007; Hoog et al, 2008, May et al, 2011 & Hogg et al, 2013.

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