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VIEWPOINT

Addressing Stigma is Not Enough

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Over the past two decades, considerable work has been done to theorize, understand, and quantify the impact of stigma and discrimination on health. Yet despite clear differences, researchers, practitioners, and donors have often designed programs, set goals, and defined indicators that fail to differentiate between the two, or that define discrimination as a sub-type of stigma.[1]

Within HIV programs, stigma is often characterized as a diffuse phenomenon that originates from multiple sources including the self and "culture".[2] Stigma-reduction programs must therefore possess a deep understanding of layered stigma, individual psychologies, and community dynamics, and be attentive to the intersectional nature of stigma—reflecting the multiple stigmas faced by people living with HIV (PLWHIV) as a result of their HIV status and identification as belonging to a "key population"—alongside racial, ethnic, and gender identities, and social class and economic status markers.

Discrimination is often defined by HIV programs, and scholars, as "structural stigma" or "enacted stigma".[3] Yet, discrimination, unlike stigma, is a human rights abuse for which there are tangible state obligations and accountability measures. The UN Committee on Economic, Social, and Cultural Rights (CESCR) defines discrimination as "any distinction, exclusion, restriction or preference… that is directly or indirectly based on the prohibited grounds of discrimination and which has the intention or effect of nullifying or impairing the recognition, enjoyment or exercise" of human rights.[4] The CESCR's authoritative statement on the right to health extensively references the importance of eliminating discrimination as a barrier to the realization of the right to health but has no mention of stigma.[5]

In her 1999 review of the literature on discrimination and health, Krieger identifies specific types of discrimination, arising from individuals and institutions, categorized as "legal, illegal, overt (or blatant), and covert (or subtle) discrimination, and also institutional (or organizational), structural (or systemic), and interpersonal (or individual) discrimination".[6] Parker and Aggleton similarly draw on a sociological understanding of discrimination as a process of dominance and subordination, and criticize the framing of

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stigma by HIV programs as "a static attitude rather than a constantly changing (and often resisted) social process".[7]

By contrast, contemporary work by scholars on stigma often acknowledges discrimination only in passing, if at all. For example, the conceptual diagram of the "Health and Discrimination Framework", presented by Stangl et al., emphasizes stigma 'experiences' and stigma 'practices'. Discrimination is identified as a type of stigmatized 'experiences' that are divided into those that "fall within the purview of the law in some places" and those that "fall outside of the law", such as gossip.[8] A review of "multi-level stigma interventions" by Rao et al. does not mention discrimination at all.[9]

The undertheorized consideration of discrimination among stigma researchers persists despite the emphasis in the Global AIDS Strategy (2021-2026) on supportive legal environments and access to justice as factors critical to a successful response to HIV and to addressing inequality.[10] This paucity of discrimination theory likely results from a lack of understanding of law and human rights among both scholars and implementors, as well as discomfort among donors to examine political or legal determinants of health.[11]

This emphasis on stigma and de-emphasis of discrimination ultimately hinders efforts to build an evidence base on the effectiveness of rights-based interventions and to secure funding for interventions grounded in legal protections for PLWHIV and key populations. Interventions that expand legal literacy and legal services, address discrimination among police and health care workers, and advocate for enabling legal environments, can increase access to prevention, testing, linkage to treatment and care, retention, and ultimately improve viral suppression.

As part of its "Breaking Down Barriers" initiative, the Global Fund in 2017 intensified its provision of technical support and increased investment to scale up these programs in 20 low- and middle-income countries. For example, in Sierra Leone, program implementers working with people who inject drugs developed a partnership with the police as a key step towards ensuring that this population could be effectively reached with HIV and harm reduction programs. [12] In Kyrgyzstan, the Ministry of Internal Affairs issued updated instructions to police to facilitate access of key populations to HIV services, such as testing and treatment, without discrimination.[13] In Mozambique, paralegal programs assisting with access to health services have expanded significantly in recent years, increasing rates of reintegration among people who had dropped out of treatment.[14] These examples demonstrate how, even in countries with repressive governments and constrained human rights environments, anti-discrimination interventions can be implemented and can be successful in reducing barriers to HIV services throughout the prevention to care continuum by expanding respect for human rights for PLWHIV and key populations.

Despite being overlooked, the evidence base for some types of anti-discrimination interventions is strong. A recent review found evidence of the impact of anti-discrimination programs for PLWHIV and key populations, ranging from decreased HIV risk behaviors to increased HIV testing and reduced incidence.[15] Advocacy targeting discriminatory laws, policies, and practices has been shown to be effective at removing barriers to HIV services, and evidence of the effectiveness of sensitizing law enforcement officials is also emerging.[16]

In 2003, Parker and Aggleton advocated that community mobilization combined with structural interventions "aimed at developing a rights-based approach to reducing HIV and AIDS-related stigmatization and discrimination" be a high priority in the HIV response.[17] Instead, efforts have prioritized biomedical approaches, marginalized rights- and community-based efforts, and underfunded civil society organizations working on anti-discrimination, accountability, and redress.[18] Where stigma and discrimination are discussed, emphasis is often put on awareness campaigns rather than rights-based anti-discrimination efforts.

Understanding discrimination as a human rights abuse for which governments have specific legal obligations facilitates a more effective response to HIV even in environments with significant, entrenched stigma. Placing discrimination within a broader political economy of social exclusion, power, and inequality, that can be best addressed with the types of programs described above, distinguishes anti-discrimination interventions from broad anti-stigma campaigns. This approach recognizes the human rights imperative to address discrimination, whether perpetuated by institutions as a result of policies and laws or advanced by individual actors. In either case, governments have an obligation to respect and protect individuals from such discrimination, and donors and others working on HIV should support governments to fulfil their rights-based obligations.

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