

# Using a Reporting System to Protect the Human Rights of People Living with HIV and Key Populations: A Conceptual Framework

R. TAYLOR WILLIAMSON, PETER WONDERGEM, RICHARD N. AMENYAH

## Abstract

Human rights of people living with HIV (PLHIV) and key populations most affected by HIV are often violated, with negative implications for health outcomes. To facilitate access to justice in Ghana, a consortium of partners developed a web-based discrimination reporting system. The reporting system links the Commission on Human Rights and Administrative Justice (CHRAJ) to civil society organizations through case reporting, follow-up, and aggregated reported data use. A reporting system can form a critical part of a country's human rights protection network. In Ghana, the combination of a supportive legal framework, an institutional home, and engaged stakeholders have created a favorable environment for developing such a system. Other institutions may learn from Ghana's experience by adapting these lessons.

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Competing interests: None declared.

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## Introduction

IN 2011, THROUGH its *Political Declaration on HIV*, the United Nations General Assembly affirmed that its members should “create enabling legal, social and policy frameworks in each national context in order to eliminate stigma, discrimination and violence related to HIV...provide legal protections for people affected by HIV...and promote and protect all human rights and fundamental freedoms.”<sup>1</sup> Following this agreement, the Joint United Nations Programme on HIV (UNAIDS) identified strengthening legal support services for people living with HIV (PLHIV) as one of seven key programs for HIV responses.<sup>2</sup>

For member states to protect the human rights of PLHIV and key populations, by which we mean men who have sex with men, sex workers and people who inject drugs, clear guidance on human rights protections relevant to these populations is required. Building on existing human rights frameworks, the UN outlined human rights principles relevant to HIV, including equal protection, privacy, education, work, security, the highest attainable standard of health, and participation in public life.<sup>3</sup> These principles should guide government responses to HIV.<sup>4</sup>

Despite UN declarations and guidance, PLHIV and key populations are still denied basic human rights globally such as housing, education, health services, livelihoods, and travel.<sup>5</sup> Legal protections are important because enshrining rights-based approaches in legislation discourages discriminatory practices.<sup>6</sup> Legal services, however, must complement legislation. Unfortunately, as of 2012, only 55% of countries provide HIV-related legal services.<sup>7</sup> Where services are available, pursuing litigation is costly and stigma can inhibit demand among PLHIV and key populations.<sup>8</sup>

This article presents a conceptual framework for an HIV and key populations-related discrimination reporting system in Ghana, supported by the Health Policy Project (HPP), a USAID-funded technical assistance project. The framework, de-

veloped to schematize operational steps to reduce discrimination, examines the role of existing policy, mechanisms for accessing justice, and capacity development strategies that influenced the reporting system design. Together, the Commission on Human Rights and Administrative Justice (CHRAJ), the Ghana AIDS Commission, HPP, and other human rights institutions applied the framework to develop a system for individuals in Ghana to report instances of HIV-related discrimination. In this paper, we outline the process and design principles used to develop the discrimination reporting system. We also present considerations for other countries that seek to provide legal services to PLHIV and key populations when their human rights are violated. Human rights commissions, ombudsman’s offices, and international assistance agencies can use our experience to inform efforts to protect PLHIV and key populations.

### Using a reporting system to protect the human rights of people living with HIV and key populations: A conceptual framework

Guidance on HIV and human rights makes clear that national HIV responses must account for various factors, such as relationships among institutional actors, legal and political environments, and social determinates of stigma and discrimination.<sup>9</sup> Building on these concepts, the authors identified three main issues to consider when strengthening legal services for PLHIV and key populations: the strengths and weaknesses of the existing legal environment, the capabilities of institutions that promote access to justice, and the mechanisms that link PLHIV and key populations to legal services.

#### *HIV-related legal and policy frameworks*

Throughout the world, legal frameworks have a significant impact on PLHIV and key populations.<sup>10</sup> While no specific legislation outlaws HIV-related discrimination in Ghana, the country’s legal frame-

work does provide broad human rights protections. Within Ghana's 1992 Constitution, Articles 17 and 29 provide for equal protection before the law, define "gender, race, colour, ethnic origin, religion, creed or social or economic status" as protected classes, and specify rights for disabled persons.<sup>11</sup> Through the previously defined protected classes, legislation protects Ghanaian citizens from discrimination in employment, education, housing, and privacy.<sup>12</sup>

Regardless of these broad human rights provisions, case law rarely defines how these provisions apply to PLHIV and key populations. As a result, there is ambiguity about which rights are legally actionable.<sup>13</sup> Of the aforementioned human rights principles, only the right to keep one's HIV status confidential has been upheld in Ghanaian case law.<sup>14</sup> However, examples of case law from other countries that protect these rights for PLHIV and key populations are common.<sup>15</sup>

Disability protections in the Ghanaian constitution and in the Persons with Disability Act can be understood to include PLHIV, though these protections have also not been codified by Ghanaian case law.<sup>16</sup> Internationally, such protections have been enshrined through case law but their application in these contexts is controversial due to the implication that PLHIV are disabled.<sup>17</sup> International experience highlights the need for supportive legal frameworks. Unlike that of Ghana, the legislative framework in Jamaica has not been interpreted to apply to HIV-related discrimination.<sup>18</sup> As a result, obtaining court-based redress is difficult.<sup>19</sup>

Punitive provision for HIV transmission and criminalization of homosexuality and sex work can also weaken human rights protections.<sup>20</sup> In Ghana, men who have sex with men and sex workers exist in a legal limbo; certain consensual sexual behaviors among adults are officially illegal, but are difficult to prosecute due to high evidentiary standards.<sup>21</sup> Regardless of criminalization, Ghanaian citizens who are members of key populations retain human rights protections through the equal protection clause of the Constitution of Ghana.<sup>22</sup>

Health-specific policies that do not carry the force of law can also provide a basis for protecting human rights. A Patient's Charter protects patients

in the Ghanaian public health system from discrimination based on culture, ethnicity, language, religion, gender, age, type of illness, or disability.<sup>23</sup> Through the prohibition of discrimination by type of illness, the Patient's Charter forbids HIV-related discrimination. The Ghana AIDS Commission (GAC) also has a National HIV/AIDS Policy that bars pre-employment HIV tests.<sup>24</sup> These policies may be enforceable within certain institutions, such as public health clinics, but are less relevant for the wider health system or labor markets. The military and police, for instance, continue to conduct pre-employment screening.<sup>25</sup>

#### *Institutions that promote access to justice*

Ensuring access to justice for PLHIV and key populations also requires strong institutions for resolving disputes. Examples of existing web-based discrimination reporting systems and human rights institutions are instructive for identifying how institutions protect the rights of PLHIV and key populations. Before designing the discrimination reporting system for Ghana, the authors studied many of these examples, both internationally and within Ghana.

We reviewed the Jamaican Network of Seropositives (JN+) experience with a web-based National HIV Related Discrimination Reporting and Redress System, where the importance of institutional capacity to support access to justice was clear. We found that JN+, the institutional home for the system, only receives complaints; it must refer cases to other institutions to seek redress.<sup>26</sup> Furthermore, JN+ has difficulty closing cases due to staff turnover, weak investigative capacity, and poor systems for referring criminal cases to prosecutors.<sup>27</sup> As a result of these challenges, case reporting is limited, with 180 complaints documented from 2005 to 2009.<sup>28</sup>

Created in 2012, Kenya's HIV and AIDS Tribunal is charged with enforcing human rights protections for PLHIV, including confidentiality breaches, health service access and discriminatory laws and policies.<sup>29</sup> Though it received 400 complaints in its first year of existence, it only delivered two judgments.<sup>30</sup> The tribunal had difficulty navigating the complex structures of Kenya's government bureaucracy that delayed redress for PLHIV, which could

cause PLHIV to lose faith in the tribunal.<sup>31</sup>

In Ghana, numerous state and non-state actors have legal protection mandates. CHRAJ is the main government institution, which has the mandate of an ombudsman's office, an anti-corruption agency, and a human rights commission. This broad mandate gives it the ability to oversee State agencies, mediate civil disputes, and conduct investigations. Though CHRAJ does not have previous institutional experience working with PLHIV or key populations, the commission handled 12,900 complaints in 2010, the vast majority of which focused on child support, child abuse, and gender-based violence.<sup>32</sup> Like HIV-related and key population discrimination, these complaints have elements of abuse, confidentiality, shame, and gender norms and dynamics. In considering how to protect the human rights of key populations, CHRAJ invoked the concept of equal protection: all citizens of Ghana have inviolable rights. The Commission has a strong national presence, with more than 700 staff, a head office in Accra, 10 regional offices, two sub-regional offices and 96 district offices. Other state agencies, such as the Ghana AIDS Commission and the Ghana Police Service's Domestic Violence and Victim Support Unit (DOVVSU), have a significant role in responding to discrimination through outreach, coordination, and case intake.

Non-state human rights organizations currently provide small-scale, fragmented legal services in Ghana. These organizations include the Human Rights Advocacy Centre (HRAC) and International Federation of Women Lawyers (FIDA), Ghana, which operate stand-alone legal clinics, paralegal services, and legal aid clinics to bring services to PLHIV and key populations.<sup>33</sup> These services are concentrated in Accra and operate with limited state resources. Though Ghanaians have the right to representation, the Legal Aid Scheme is poorly resourced and staffed.<sup>34</sup> As a result, the scheme is not often accessed by members of key populations who face criminal proceedings.

#### *Mechanisms to link people living with HIV and key populations to legal services*

Supportive legal frameworks and institutions are

not enough to ensure legal service for PLHIV and key populations. Mechanisms, such as networks and partnerships, must exist to link legal services to people who need them. This is the final element of our framework.

In India, grassroots outreach strengthened legal service scale-up in Tamil Nadu and Andhra Pradesh states, where a partnership between UNDP and the National AIDS Control Organization created legal clinics. This partnership connected networks of PLHIV, the State AIDS Control Societies, and legal aid attorneys to provide legal services.<sup>35</sup> In each clinic, staff conducted intake interviews, raised awareness about rights and services, and referred cases to pre-identified attorneys.<sup>36</sup> UNDP noted that strong partnerships with networks of PLHIV were critical: they supported outreach efforts to create demand.<sup>37</sup> Government institutional ownership and buy-in were also important to project success.<sup>38</sup>

As there was little documented information on functional mechanisms in Ghana that link PLHIV to legal services, the authors also held discussions with technical working groups, human rights organizations, CHRAJ, PLHIV, and key populations in Ghana to understand existing mechanisms for linking PLHIV and key populations to legal services. These discussions revealed significant service fragmentation, few referral procedures, and little trust between civil society, PLHIV, key populations, and legal service providers.

As a result of this fragmentation, GAC and CHRAJ, with HPP support, began designing a discrimination reporting system for Ghana that would be institutionalized within CHRAJ. This reporting system built on the three elements of the conceptual framework by utilizing the legal environment, building on existing institutional capacity, and strengthening ties between PLHIV and legal services.

#### Reporting system development process

Following the decision to develop a discrimination reporting system, the authors conducted further key informant interviews and focus groups to better understand the legal environment, further define

institutional actors, identify system requirements, and specify barriers to access. HPP, CHRAJ, and GAC created a multisectoral oversight body, the Reporting System Committee, that included civil society and affected populations to guide and monitor implementation of the system. The committee included representatives from the various organizations that provided input on improving legal support services. Its mandate was to oversee reporting system implementation, providing a forum for civil society, GAC, and CHRAJ to discuss policy development, demand generation, and progress of cases.

As the first step to institutionalize the system within CHRAJ, HPP conducted an assessment of CHRAJ's capacity to manage HIV-related discrimination cases. This assessment identified four main areas of need: 1) policy and procedure gaps; 2) CHRAJ staff training; 3) information technology (IT) infrastructure; and 4) demand generation.

CHRAJ addressed policy and procedural gaps by creating a Health Rights Task Team to oversee case routing and develop a new privacy and confidentiality policy. CHRAJ is currently taking cases through the reporting system, conducting case investigations, and finalizing a privacy and confidentiality policy.

CHRAJ officers also needed training to sensitively and professionally manage cases of discrimination against PLHIV and key populations. In January 2013, HPP conducted a stigma reduction training, and in November, a more targeted training focused on the Health Rights Team. As front desk staff were also likely to come in contact with clients, they received a condensed version of the stigma-reduction training, which was then embedded into CHRAJ on-boarding training procedures to ensure institutionalization.

CHRAJ also faced a number of IT challenges such as outdated servers, US-based web hosting, and a non-functional case management system. To streamline case reporting and monitoring, the reporting system had to be integrated into existing CHRAJ systems. Integration, however, required updates to CHRAJ's IT infrastructure, including servers and web hosting.

The success of the system depends on PLHIV

and key populations reporting cases of discrimination. To that end, the Reporting System Committee is building demand by engaging PLHIV and key populations in peer-to-peer outreach and incorporating outreach into CHRAJ's public education strategy. Future evaluation will consider the effectiveness of these approaches through counting in-person contacts and system referrals.

## System design

Based on the conceptual framework, Reporting System Committee input, and focus groups with PLHIV, the authors designed a system for PLHIV and key populations to report cases of discrimination to CHRAJ. This reporting system uses both a web-based and an SMS (short message service) reporting system to build on existing structures. If using the web-based system, a complainant has two options. First, an individual may bring the case to the attention of a partner human rights organization, which then reports it to CHRAJ through the web-based reporting system. Second, a complainant may report a case directly through the web-based system. The first mechanism allows clients to remain anonymous and provides the institutional backup of the civil society partner, while the second option allows clients to work directly with CHRAJ, but will not allow them to remain anonymous if they are seeking redress. If they are not seeking redress and only wish to report a case of discrimination, complainants may retain anonymity, regardless of the procedure used.

An SMS reporting option also exists. People living with HIV and key populations who have experienced discrimination may text complaints directly to CHRAJ. The limited information carried by SMS requires CHRAJ staff to call, text, or request an in-person interview with the client to process a complaint.

Following case submission, CHRAJ moves the complaint through a three-step process:<sup>39</sup>

- Mediation: The parties seek to resolve their differences through CHRAJ-facilitated negotiation.<sup>40</sup>

- Investigation: CHRAJ researches the complaint and provides a recommendation.<sup>41</sup>
- Adjudication: CHRAJ can enforce its recommendation through a court order.<sup>42</sup> Possible remediation options include fines, reinstatement, and sanctions against public officials.<sup>43</sup>

The reporting system also facilitates accountability by allowing human rights organizations to access updates for cases they submitted, contact CHRAJ case officers to inquire about progress, and provide case-relevant documentation. Aggregated data on reported complaints are also available and can inform future advocacy efforts. With aggregated data, the CHRAJ Health Rights Task Team can calculate case submission, response, and closure rates, as well as the average time for cases to move through the system. These metrics will be provided to the Reporting System Committee and compared with CHRAJ standards to evaluate system performance.

Finally, the system allows CHRAJ to refer cases to legal service organizations. Situations in which CHRAJ may be unable to act on a complaint include: if a lawsuit has already been brought to court, if an incident occurred more than 12 months ago, and if CHRAJ deems the complaint to be trivial or frivolous.<sup>44</sup>

### Implications for other countries

There are similarities and differences among the experiences in Jamaica, India, and Kenya, and the system in Ghana. In Jamaica, the web-based reporting system is managed by a network of PLHIV, not a government agency. JN+ must refer cases to other organizations that provide legal services. In India and Kenya, legal service capability is embedded in the institutional home, but no web-based platform exists to connect clients and legal service providers. India used low-tech methods to build demand, and its experience highlights the importance of grassroots outreach. In Kenya, the HIV and AIDS Tribunal was embedded in the judiciary, without specific legal representation for PLHIV or key populations. All three country examples revealed that underreporting was a significant problem. These examples

suggested different methods of generating demand: ensuring redress options, facilitating reporting, and grassroots engagement.

Building on the elements of the conceptual framework, the authors identified lessons for the development of future reporting systems:

- Ensure a legal basis for redress exists and that lawyers understand it
- Institutionalize the system within the right organization
- Engage a variety of partners at multiple steps

Experience from Jamaica suggested that underuse of legal services was driven by poor redress options for PLHIV and key populations. Civil society partners in Ghana wanted the reporting system to be more than a database of complaints; they thought that the system must help CHRAJ ensure access to justice for complainants. CHRAJ's ability to enforce recommendations through the court system is a significant strength and addresses concerns about how to ensure redress.

The Jamaican and Indian examples, as well as stakeholder discussions in Ghana, demonstrated a number of critical attributes for any institutional home: a human rights mandate, trust with affected communities, knowledge of human rights frameworks, connections with legal service providers, the ability to coordinate stakeholders, geographic reach, strong institutional commitment to address discrimination, supportive policies and procedures, and up-to-date IT infrastructure. CHRAJ's human rights mandate was a key factor in the decision to institutionalize the reporting system within the commission. Significant senior management support improved institutionalization: they continue to lead planning sessions, oversaw system design, and devoted resources to fill institutional gaps. CHRAJ also had challenges to overcome, such as its lack of experience with PLHIV and key populations, weak IT infrastructure, and poor privacy and confidentiality policies. In other countries, different needs and concerns may arise during system development and use in other settings.

Finally, civil society, governments, PLHIV, key

populations, legal support organizations, and social service providers must be engaged to guide system design, generate demand, and oversee implementation. They can also provide key technical guidance on country-level issues, such as the specifics of the country's HIV epidemic and civil society structures. In Ghana, stakeholders are engaged at multiple points in planning, designing, and implementing the system, helping to make the system more user-friendly, identify and fill technical gaps, hold CHRAJ accountable, and build demand.

A reporting system can form a critical part of a country's human rights protection network. In Ghana, the combination of a supportive legal framework, an institutional home with the right mandate and capacity, and engaged stakeholders have created a favorable environment for developing such a system. As a result, we have made important strides toward linking government and civil society to address human rights violations against people living with HIV and key populations. We hope that other countries can use the lessons we've learned to consider how a reporting system can strengthen human rights protections for PLHIV and key populations.

### Acknowledgements

The authors would like to thank all the stakeholders involved in the development of this reporting system, from both civil society and government. Specifically we would like to thank the Honourable Nana Oye Lithur, Minister of Gender, Children and Social Protection in Ghana, who provided a great deal of background information; Isaac Annan, who provided draft comments; Joseph Whittal, Clement Tahiru, Eugenia Appiah, Isaac Annan, Festus Mensah, and the Health Rights Task Team at the Commission on Human Rights and Administrative Justice; Fred Nana Poku, Cosmos Ohene-Adjei, John Mahama, and Angela El-Adas at the Ghana AIDS Commission; and Vivian Fiscian, for her support to CHRAJ. Dara Carr, Lory Frenkel, and Elizabeth T. Robinson of the Health Policy Project/Futures Group, and Laura Nyblade, Health Policy Project/RTI International, provided editorial guidance. In addition, we are grateful to our colleagues Ron Ma-

Innis, Health Policy Project/Futures Group, who worked on the conceptualization and oversight of the reporting system; and Kip Beardsley, Health Policy Project/Futures Group, for his insights on international efforts upon which the Ghana reporting system builds.

This paper was supported by the Health Policy Project, a five-year cooperative agreement funded by the US Agency for International Development under Agreement No. AID-OAA-A-10-00067, beginning September 30, 2010; this activity was also supported by the US President's Emergency Plan for AIDS Relief (PEPFAR). We would like to thank USAID for its ongoing financial support for the reporting system.

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