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DESIGNING A DISCRIMINATION MONITORING, REPORTING, AND REFERRAL SYSTEM



*International Best
Practices and Current
Policy, Practice, and
Opportunities in Ukraine*

This publication was prepared by Alla Boyko and Kipling Beardsley of the Health Policy Project and Christopher Wild of the U-Media Project.



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Designing an Effective HIV Discrimination Monitoring, Reporting, and Referral System

International best practices and current policy,
practice, and opportunities in Ukraine

JUNE 2012

This publication was prepared by Alla Boyko¹ and Kipling Beardsley¹ of the Health Policy Project and Christopher Wild² of the U-Media Project.

¹Futures Group, ²Internews

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ABBREVIATIONS

ADCQ	Anti-Discrimination Commission Queensland
AIDS	acquired immune deficiency syndrome
CSW	commercial sex worker
CQC	Care Quality Commission
EEOC	Equal Employment Opportunity Commission
FSW	female sex worker
GNP+	Global Network of People Living with HIV
GOU	Government of Ukraine
HIV	human immunodeficiency virus
HPP	Health Policy Project
ICW	International Community of Women Living with HIV
IRF	International Renaissance Foundation
LGBT	lesbian, gay, bisexual, transgender
LGBTI	lesbian, gay, bisexual, transgender, intersex
MAT	medication-assisted therapy
MOH	Ministry of Health
MSM	males who have sex with males
NGO	nongovernmental organization
PLHIV	people living with HIV
PWID	people who inject drugs
STI	sexually transmitted infection
SW	sex worker
UFLS	Ukrainian Foundation of Legal Support
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
USCP	USAID HIV/AIDS Service Capacity Project in Ukraine

INTRODUCTION

People in communities worldwide continue to experience HIV-related stigma and discrimination—for example, while trying to access healthcare services, rent an apartment, or apply for employment or education. In particular, HIV-related stigma and discrimination are still an everyday reality—for people living with HIV (PLHIV), as well as people at higher risk of HIV (key populations). The importance of creating a mechanism for community members to systematically report incidences of discrimination is paramount. Equally important is ensuring that people feel safe in reporting incidences to authorities and believe that such reporting will produce results.

While national-level laws in Ukraine are designed to protect PLHIV and key populations from discrimination, a lack of enforcement, education, promotion, and monitoring of these laws severely limits their overall effectiveness. Moreover, existing systems that document and resolve cases of discrimination are often isolated from each other, limited in scope and specificity, and solely dependent on international donors.

Effectively capturing and reporting discrimination data can help an organization or government administration gauge the level of discrimination in a country and ensure effective responses. However, there is no standard design for discrimination monitoring and reporting. The system should incorporate known best practices, but it should also be informed by local needs, resources, and policy environments.

This report brings together international best practices, research on the existing legal codes and systems in Ukraine, and information from consultations with key stakeholders to determine priorities and approaches for monitoring discrimination. The structure and content of the report contains best practices from a diverse sampling of discrimination monitoring and resolution systems with the intent to draw on lessons learned in non-health sectors. The report also documents the process of defining and refining scope and scale of a potential system—with the inclusion of topics such as stigma that were part of early discussions but that were eventually not prioritized for incorporation into the final system design.

The document is intended to be the beginning of a conversation on monitoring, reporting, and resolving cases of discrimination for PLHIV and vulnerable populations in Ukraine. As there are many related and complex issues for which there are reasoned and yet contradictory perspectives, the document does not provide a definitive stand. Rather, it reflects the status of the conversation and identifies potential recommendations for the Ukrainian context.

A Key to Stopping the Epidemic

“HIV/AIDS-related stigma and discrimination are an everyday reality. Stigma and the fear of discrimination often stop people from seeking to be tested for HIV, or from acknowledging their HIV status publicly. People living with, or suspected of having, HIV are sometimes denied treatment by medical practitioners, housing by landlords, and jobs by employers. They may sometimes be shunned by their families, friends, and colleagues; turned down for insurance coverage; or refused entry into foreign countries.

Reducing the stigma and discrimination surrounding HIV/AIDS is key to both stopping the spread of the epidemic and improving the quality of life of people living with the disease. The perception of HIV/AIDS as a disease affecting only, or primarily, groups such as gay men, sex workers, or people who use drugs can lead to little or no attention paid by governments to the disease. Yet, governments have a legal responsibility to take action, and everyone has a role to play.”

Source:

www.aidslaw.ca/discrimination

As noted in this document, recommendations for the future design of a monitoring, reporting, and referral system for stigma and discrimination include the following:

1. Engaging donors for financial and technical support. In the short term, donors appear to be the most viable source of financial and technical support for designing and implementing a monitoring, reporting, and referral system. Local capacity building and increased technical and financial resources will be needed to make the system sustainable and ensure the efficiency and effectiveness of government organizations charged with the protection of human rights in Ukraine.
2. Considering the cultural, legal, and policy contexts. Design and implementation of a discrimination monitoring, reporting, and referral system must be done with an awareness of the overall cultural, legal, and policy context and must contribute data to and collaborate with ongoing efforts for the reform of the legal code and policy implementation.
3. Monitoring the effectiveness of government and private sector resources. Discrimination monitoring, reporting, and referral systems should collect and disseminate information on the effectiveness of government and private sector resources for resolving cases.
4. Recognizing the important role of nongovernmental organizations (NGOs). NGOs are key players in monitoring and protecting the rights of citizens and thus should be part of the system.
5. Generating usable data. Data from the monitoring system should be made available to the public, coordinated with and contribute to national and international NGO-sector reporting opportunities, and be used to reinforce and triangulate data on stigma and human rights.
6. Protecting individual information. Any disaggregation of data must not inadvertently disclose personally identifying information.
7. Focusing on cases of discrimination. The monitoring, reporting, and referral system in Ukraine should focus on cases of discrimination. Reporting and monitoring of stigma is more appropriate for regular population-based surveys and periodic research.
8. Responding to discrimination against PLHIV and members of key populations. HIV-related stigma affects both individuals who are HIV positive and those who are members of populations at higher risk for HIV.
9. Focusing on healthcare and law enforcement. Because of the overwhelming scale of discrimination and the direct impact on HIV-related morbidity and mortality, the system in Ukraine should primarily focus on the health and legal sectors. However, the system should not preclude cases of discrimination in other areas or sectors when they arise and opportunities should be identified to engage other sectors (e.g., education, labor, housing, etc.) in systemic monitoring, reporting, and resolving cases of HIV-related discrimination.
10. Engaging and supporting government structures. The efforts to monitor, report, and resolve cases of discrimination in Ukraine need to identify opportunities to support the efficiency and effectiveness of government organizations charged with the protection of human rights.
11. Exploring use of new technologies. New technologies present opportunities to create a standard data collection and reporting platform that allows for both passive and active data collection and multiple points of access (e.g., via Web, phone, in person, by third party).
12. Ensuring public awareness of resources. Any activity to monitor, report, or resolve cases of discrimination must include a public awareness component, especially targeting marginalized populations that are less likely to access related resources.

DEFINITIONS OF TERMS

Terms should be defined to provide a common language among stakeholders, advocates, and users of stigma and discrimination reporting and referral systems and their results.

Discrimination: An *action* based on a pre-existing stigma; a display of hostile or discriminatory behavior toward members of a group, on account of their membership to that group. Whereas stigma deals with belief systems and often deeply seeded feelings, discrimination relates to the actions that people carry out as a result of stigma.

There are several types of discrimination:¹

- *Direct discrimination*—when an individual is less favorably treated because of characteristics as defined in local laws and regulations. For example, two applicants apply for an apartment and one of the applicants is a married couple while the other is a single man. The single man happens to have a better credit rating, but the apartment is given to the married couple based on perceptions that they will be more stable tenants.

The covered bases (see box and definition on page 5) of individuals protected from discrimination and the sectors where this protection applies will be dependent on local country law. The Office of the United Nations High Commissioner for Human Rights provides the following summary of international nondiscrimination principles:

“The right to equality and the principle of non-discrimination are among the most fundamental elements of international human rights law. The right to equality guarantees, first and foremost, that all persons are equal before the law, which means that the law shall be formulated in general terms applicable to every human being and enforced in an equal manner. Secondly, all persons are entitled to equal protection of the law against arbitrary and discriminatory treatment by private actors. In this regard, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on the grounds of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, disability and health status, including HIV/AIDS, age, sexual orientation, or other status.”²

In the workplace, employers will usually be required to mirror country laws and may have policies that include language such as follows:

“The employer is an ‘equal opportunity employer.’ The employer will not discriminate and will take ‘affirmative action’ measures to ensure against discrimination in employment, recruitment, and advertisements for employment, compensation, termination, upgrading, promotions, and other conditions of employment against any employee or job applicant on the bases of race, creed, color, national origin, or sex.”³

However, there may be exemptions to discrimination regulations for specific organizations, such as religious organizations or small family businesses.

¹ **Compact Law.** “Discrimination—An Introduction to Discrimination Laws.” Copyright 1996–2011. Accessed December 2011: <http://www.compactlaw.co.uk/free-legal-information/employment-law/discrimination-introduction.html>.

² Office of the United Nations High Commissioner for Refugees. Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies. HR/PUB/06/12, p. 9.

³ See smallbusiness.findlaw.com/employment-employer/employment-employer-discrimination/starting-business-employment-anti-discrimination-policy.html.

- *Indirect discrimination*—when the effect of certain requirements, conditions, or practices imposed by an employer has an adverse impact disproportionately on one group or another. This is a less obvious form of discrimination. With indirect discrimination, an employer can argue that there may be discrimination but that it is actually required for the job; this is known as a Genuine Occupational Requirement or a Bona Fide Occupational Qualification. This does not happen often, but circumstances when it may occur include, for example, when actors are needed to play certain characters for authenticity. The same can be true for restaurants (e.g., an Indian restaurant will want Indian staff rather than white staff) or places catering to specific clientele (e.g., an all-female hostel will want to employ women staff).

For example, random or mandatory drug testing may prove to be indirect discrimination for people who inject drugs. Whether or not this is classified as a Genuine Occupational Requirement, guidance from Canada, for example, indicates that

Random alcohol testing of employees in safety-sensitive jobs may be allowed on the basis that a properly administered breathalyzer can indicate actual impairment of ability to perform or fulfill the essential duties or requirements of the job. By contrast, random drug testing is prohibited because drug testing can only detect the presence of drugs and not if or when an employee may have been impaired by drug use. The policy identifies a ‘safety-sensitive’ job as one in which incapacity due to drug or alcohol impairment could result in direct and significant risk of injury to the employee, others or the environment.

The Canadian Human Rights Act prohibits discrimination on the basis of disability and perceived disability and ‘disability’ includes a previous or existing dependence on drugs or alcohol. So an employer has a duty to accommodate an employee who has tested positive with individualized or personalized accommodation measures.^{4, 5}

In the case of indirect discrimination based on HIV status, while it is difficult to identify a circumstance where discrimination would be warranted, the legal field is still wrestling with this issue and how to balance the rights of PLHIV with potential (however statistically insignificant) risks of transmission—especially for individuals who are HIV positive and working in the healthcare sector.

Harassment: Harassment is unwelcome conduct that is based on characteristics protected from discrimination in national laws. Harassment is often defined as unlawful when (1) enduring the offensive conduct becomes a condition of continued employment or receipt of benefits or (2) the conduct is severe or pervasive enough to create an environment that a reasonable person would consider intimidating, hostile, or abusive.

Anti-discrimination laws often also prohibit harassment against individuals in retaliation for filing a discrimination charge, testifying, or participating in any way in an investigation, proceeding, or lawsuit under these laws; or opposing employment practices that they reasonably believe discriminate against individuals, in violation of these laws.

⁴ Ontario Human Rights Commission. Policy on Drug and Alcohol Testing. Available at: www.ohrc.on.ca/en/resources/Policies/PolicyDrugAlch/pdf.

⁵ Entrop v. Imperial Oil, Ltd. Available at: www.employmentlawtoday.com/ArticleView.aspx?l=1&articleId=1343.

Petty slights, annoyances, and isolated incidents (unless extremely serious) will not usually rise to the level of illegality. To be unlawful, the conduct must create an environment that would be intimidating, hostile, or offensive to reasonable people.⁶

Victimization: Where someone is singled out for using complaint procedures or exercising their legal rights. For example, bringing a complaint of discrimination or giving evidence or information on behalf of another client who has brought proceedings for discrimination. Individuals will not usually be protected by the law if they have maliciously made or supported a complaint that is false.

Stigma:⁷ The holding of derogatory social *attitudes* or cognitive beliefs, a powerful and discrediting social label that radically changes the way individuals view themselves or the way they are viewed by others.

Covered bases: Individual attributes that may be the result of biological factors (e.g., sex, race, age, sexual orientation, etc.) or choices (e.g., religion, political party affiliation, relationship status, etc.) or circumstances (e.g., refugee status, disability, etc.). Laws will usually describe which of these attributes are protected from discrimination in each country.

Timeframe/statute of limitations: The amount of time a person has to file a claim after the discrimination has occurred. For example, in the United States, one must file a charge within 180 calendar days from the day the discrimination took place. The 180 calendar day filing deadline is extended to 300 calendar days if a state or local agency enforces a law that prohibits employment discrimination on the same basis. The rules are slightly different for age discrimination charges. For age discrimination, the filing deadline is only extended to 300 days if there is a state law prohibiting age discrimination in employment and a state agency or authority enforcing that law. The deadline is not extended if only a local law prohibits age discrimination.⁸

Unlawful Treatment

The Anti-Discrimination Commission of Queensland in Australia, for example, states: Your treatment may be unlawful if it fits in both categories 1 and 2.

Category 1—you or your presumed

- sex
- sexuality
- gender identity
- lawful sexual activity as a sex worker
- relationship status
- parental status
- family responsibilities
- pregnancy
- breastfeeding
- age
- race
- impairment
- religious belief, non-belief or activity
- trade union activity
- political belief or activity or
- association with a person identified by one of the above grounds

Category 2—while you are

- working, applying for a job, doing work experience or volunteer work
 - obtaining goods or services-at a shop, café, pub, bank, doctor, taxi or car yard
 - accessing premises or facilities
 - obtaining state government or local council services
 - going to school, college, university or other place of education
 - renting or getting other accommodation
 - applying for insurance or superannuation
 - buying real estate
 - joining or as a member of a club (non-profit clubs like bowls clubs are not covered but night clubs are)
 - being a member of a local council
- (See Annex A)

⁶ U.S. Equal Employment Opportunity Commission. *Types of Discrimination*. Accessed December 2011: www.eeoc.gov/laws/types/index.cfm.

⁷ Rose Smart. Module 1.4. HIV-related Stigma and Discrimination. Available at: www.iiep.unesco.org/fileadmin/user_upload/Cap_Dev_Training/pdf/1_4.pdf.

⁸ Equal Employment Opportunity Commission. *Time Limits for Filing a Charge*. Available at: www.eeoc.gov/employees/timeliness.cfm.

FUNDAMENTAL ETHICAL PRINCIPLES

Regardless of the design, scope, or scale of a reporting and referral system, fundamental ethical principles should underlie its design and implementation. Discussions among stakeholders in Ukraine identified the following fundamental ethical principles for a reporting system.

Minimize the potential for harm. Reporting systems should not jeopardize the health and well-being of claimants and should not place individuals at greater risk of discrimination or criminal investigation. The reporting system must be designed to provide the maximum protection for claimants within the cultural and legal codes of the country and must clearly disclose any potential for harm to individuals who seek help. For example, this would apply if a person who injects drugs reports a healthcare worker who discriminates against him or her on the basis of either HIV status or drug use and this report is then used to initiate a criminal investigation or document behavior that is criminalized.

Maintain confidentiality. Information collected must be kept confidential, and the disclosure of identifying data (e.g., for resolution of cases) must be authorized by the claimant with full disclosure of any potential that the data may be used against them. Data that identifies individuals should only be kept as long as it is necessary and should be removed from permanent databases and files.

Clarify the expectations that claimants can have of the reporting system. Claimants should know how and if their case data will be used. There should also be clear information about what kind of cases are usually eligible for resolution, if there is a referral process for resolution, and what the usual timeframes are for reporting and resolution.

Design a reporting system only when there is a purpose/reason. Data should not be collected simply for the sake of collecting data. The reporting system should be designed to disseminate data on stigma and discrimination, influence discrimination policy and programs, and/or to facilitate the resolution of cases.

Balance promises with resources. If a country has limited or ineffective organizations or resources to advocate for the resolution of cases, the reporting system should not promise to provide referral and facilitation of case resolution.

Enable case verification. It is important to protect the long-term credibility of antidiscrimination advocacy efforts. Therefore, it is important that information on the elements required for case validity be clearly described to claimants and advocates so that they can accurately assess the validity of their claim.

Support broad anti-discrimination efforts. While this document and the systems that it describes primarily refer to issues of discrimination based on HIV status and membership in a vulnerable population, discrimination is widespread in society for many individuals. Organizations addressing discrimination in any form have the opportunity to integrate and collaborate with each other and create broad advocacy coalitions.

THE LEGAL CODE OF UKRAINE

The legal code of Ukraine provides for strong discrimination protections and creates a legal norm of prohibition of discrimination in any form, including in the workplace through a current draft Labor Code that has been submitted to Parliament but not yet adopted in Ukraine.

Specific protections against discrimination for PLHIV and vulnerable populations

The Ukraine legal code contains specific laws prohibiting discrimination on the basis of sex,⁹ age,¹⁰ and HIV status and being part of an HIV-related vulnerable group. Specifically, “discrimination is action or failure to act that directly or indirectly creates limitations, deprives people of the rights they are entitled to or violates their human dignity on the basis of one or more symptoms associated with actual or possible fact of having HIV, or gives grounds to attribute such people to groups at high risk of HIV.”¹¹ This same law identifies the specific realms in which discrimination based on HIV status is prohibited, including employment, education, medical services, and social care and support (Article 16). Protections are also provided for additional groups of people such as those with physical or mental handicaps, racial and ethnic minorities, refugees, and religious practice through international conventions ratified by Ukraine. However, these international documents are rarely applied to protect human rights.

The Government of Ukraine is also in the process of approving the Human Rights Anti-Discrimination Strategy of Ukraine. The draft strategy was developed by the Ministry of Justice and approved at the Government of Ukraine meeting on February 15, 2012. Key provisions of the draft strategy are expected to improve anti-discrimination legislation and intensify the international collaboration in this area. In addition, the government is encouraged to ensure the legal, medical, and social support to people who have been discriminated against. The strategy also identifies a priority for the government to support and promote tolerance in the general population toward individuals of different skin color, race, political, religious and other beliefs, sex, ethnic origin and social background, property status, area of residence, language, etc., as well as on promotion of multicultural values.

In Ukraine, there are no organizations that are exempt from anti-discrimination legislation.

Instances of discrimination by means of de facto criminalization

In Ukraine, there are no laws that explicitly **allow** discrimination on the basis of HIV status, drug use, provision of commercial sex services, or sexual orientation. However, while addiction is officially considered a disease, the possession any amount of drugs for personal use above very low threshold amounts (which would include residual drugs left in syringes) qualifies for criminal liability. Similarly, providing commercial sex services involves administrative liability under the Code of Ukraine on administrative offenses.

⁹ Law of Ukraine “On Equal Rights and Opportunities for Women and Men.” # 2866-IV as of 8 Sept 2005

¹⁰ Law of Ukraine “On basic social protection of labor veterans and other elderly people in Ukraine.” # 3721-XII as of 16 Dec 1993

¹¹ Law of Ukraine “On response to transmission diseases caused by the Human Immunodeficiency Virus (HIV) and legal and social protection for people living with HIV.” # 1972-XII as of 12 Dec 1991

Protection from prosecution for filing discrimination complaints

Individuals who file a complaint of discrimination, like other claims related to any violation of the rights of citizens of Ukraine, are protected from prosecution by the Laws of Ukraine,¹² which outline the mechanisms of exercising the citizens' rights to appeal against actions of officials. This law provides protection from prosecution for citizens and their families on the grounds that they are appealing against the actions or inaction of officials.

Statute of limitations

The statute of limitations in Ukraine for filing a case for protection of civil rights or interest is three years. The timeframe for appeal against decisions and actions or inaction of state authorities or local government is one year. This period starts with the day when the person learned or could learn about the violation of his/her rights or about the person who violated it.

Examples of remaining stigmatizing elements of legal code

While, in general, laws in Ukraine align with international best practices, a few components of the legal code remain stigmatizing:

- A low threshold amount of opium that qualifies as illegal drug possession and criminal liability¹³
- Criminal liability for HIV transmission to a partner even with disclosure¹⁴
- A lack of liability for disclosure of HIV status in non-medical settings¹⁵
- Statutes that equate people with disease to criminals, provide for disclosure of status, and legalize violence against people living with HIV and representatives of vulnerable groups only on the basis of HIV-positive status and membership of a vulnerable group¹⁶
- Identification of sexual orientation, rather than unsafe sexual behavior, as exclusionary criteria for blood donation¹⁷
- Named reporting of HIV infection¹⁸
- Requirements for the disclosure of children's HIV-positive status to health workers of day care/preschools, schools, and higher education facilities¹⁹

System to provide free legal services

While a recent government directive has taken the initial step of allocating budget funds to pay legal fees for low-income individuals in criminal cases,²⁰ more efforts are needed to provide resources for individuals with discrimination and human rights cases and to enforce and implement these services.

¹² "On citizens' appeals," "On the safety of people involved in criminal proceedings," which states that the people who appealed to the law enforcement authorities on a crime, victims and their close relatives have the right to ensured security.

¹³ MOH Order # 634 as of 29 JUL 2010.

¹⁴ Article 130 of the Criminal Code of Ukraine "HIV Infection." # 2341-III as of 5 Apr 2001

¹⁵ Article 132 of the Criminal Code.

¹⁶ Article 10, Law of Ukraine "On the Militia." # 565-XII as of 20 Dec 1990

¹⁷ MOH Order # 385 as of 1 Aug 2005 "On the infection safety of donor blood and its components," Annex # 3

¹⁸ Joint Order of the MOH, State Statistic Committee Order # 640/663 as of 24 Dec 2004 in the Section "Instructions for filling out a form of primary reporting # 502-2/o "Notification of changes in Registration Card of HIV-infected people."

¹⁹ Joint Order of the Ministry of Health of Ukraine, Ministry of Education and Science of Ukraine, Ministry of Family, Youth and Sport of Ukraine, State Penitentiary Department of Ukraine, Ministry of Labor and Social Policy of Ukraine #740/1030/44/321/614a as of 23 Nov 2007, "On efforts on organization of prevention of mother to child transmission of HIV, medical care and social support for HIV-infected children and their families."

²⁰ CMU Directive "On Amending the Procedure for the Use of State Budget Funds to Provide Individuals with Free Support in Criminal Cases" (2012) to support implementation of law of Ukraine on "Free Legal Support" (2011) for all people of Ukraine.

Difference between the law and implementation

The differences between the provisions of law and the practice of policy implementation highlight the fact that in Ukraine the legal norms remain primarily declarative in general, especially for people living with HIV and members of vulnerable groups. Research conducted by Ukrainian and international NGOs documented violations such as violation of confidentiality and disclosure of HIV diagnosis, testing without consent, coercive abortion, denial of access to education, retention of children in hospital wards instead of placement to boarding schools, denial of delivering ART to drug users, separation of HIV-positive mothers and their newborns immediately after giving birth, arbitrariness of the law enforcement authorities, and others.

Resource

Organization for Security and Cooperation in Europe (OSCE) Rule of Law and Human Rights

www.osce.org/uk/ukraine/70257

In addition, the inadequate system of enforcement of laws, the corrupt judicial system in Ukraine, ignorance of people living with HIV on their rights and benefits and their self-stigmatization are also barriers, which impede accessing the legally declared rights of PLHIV. It is also important to note that the degree of social tolerance in Ukrainian society is decreasing, which also prevents PLHIV and vulnerable populations from standing up for their rights.

Recommendation

- Design and implementation of a discrimination monitoring, reporting, and referral system must be done with an awareness of the overall cultural, legal, and policy context and must contribute data to and collaborate with ongoing efforts for the reform of the legal code and policy implementation.

OVERALL PURPOSE OF THE SYSTEM

In the design of a discrimination monitoring, reporting, and referral system, three primary purposes were identified in international systems and by stakeholders for Ukraine: referring individual cases to resolution, report aggregated data, and informing community and advocacy efforts.

Referral of individual cases to resolution

With a primary purpose of facilitating referral of cases to resolution, a **case reporting system** will need to be established and this system will need to collect personal data.

Data protection

Once a reporting system starts to collect personal data, data protection becomes a significant concern. One of the most sensitive issues facing those who might want to file a claim relates to confidentiality. It can take tremendous effort and courage to speak up about experiencing discrimination, and a person wonders what will happen to his or her name or information after officially filing a complaint. Depending on what type of discrimination takes place, the event can be quite traumatic and the person might be reluctant to share such personal information.

Policies on Confidentiality

The Anti-Discrimination Commission of Queensland Complaint Form states "Everything you send us including your address for service, will be copied and sent to the people you are complaining about. If you don't want your details given out, contact the Commission to discuss your options."
(See Annex A)

Disclosure to claimants on level of confidentiality to be expected from monitoring/reporting system

The reporting system will need to explain how the existing laws and policies will impact the level of confidentiality that can be assured for data associated with discrimination cases. It will also be important to give claimants the choice of whether or not to disclose their data. However, if they choose to not disclose their personal data, claimants will need to understand that the processes for resolution may be more limited.

It is important to make sure that claimants understand that when seeking referrals to resolve their complaint, disclosure of their personal data may be necessary to advocacy organizations, the offending party, and perhaps to legal proceedings where the information may become part of the public record.

If legal protections do not exist for the use of data collected in the course of a discrimination complaint or resolution in criminal investigations or cases, incriminating information should not be collected. Wording, both on written materials (including websites) and in in-person interactions, should inform potential claimants of any potential risks of sharing information about criminalized behaviors. If, however, there are legal protections against the use of claimant information in criminal proceedings, then this should also be disclosed and adhered to. In any trainings or public information campaigns done to promote the reporting system, this should also be mentioned and explained so that implementers understand the importance of this issue.

Anonymous claims

With regard to anonymity, systems should encourage people to come forward with discrimination charges or reports, even if they do not wish to identify themselves. And while referral and resolution options for anonymous cases may be limited, this reporting contributes to the broader documentation of social disparities. There should be a mechanism for accepting anonymous reports or reports from friends or family members who file a charge to protect the anonymity of the victim. Procedures for filing anonymous reports should be stated clearly for the public to access.

Validation of claims

It is beyond the purview of a discrimination reporting and referral system to make judgments on the validity of discrimination claims—this falls under the responsibility of lawyers, mediators, or courts. However, it is helpful for the reporting and referral system to provide information to potential claimants and advocates on the elements that will be evaluated in the process of validating discrimination claims. For example, the U.S. Equal Employment Opportunity Commission (EEOC) has identified six elements²¹ that must be satisfied for a claim to be considered valid. These elements include the following:

- Covered bases—is the complaint based on characteristics protected by law (e.g., age, sex, etc.)?
- Covered issues—is the complaint based on practices that create a liability under local law (e.g., differences in pay or promotion or access to public services based on covered bases)?
- Covered individuals—does the complaint cover an individual who is protected by law (e.g., employee, student, tenant, patient, etc.)?
- Timeliness—has the complaint been filed within the time limitations of the law?
- Standing—is there evidence of an adverse impact?

²¹ U.S. Equal Employment Opportunity Commission. *Compliance Manual—Threshold Issues*. Available at: <http://www.eeoc.gov/policy/docs/threshold.html>.

If the complaint is found to meet these elements, then it is eligible for investigation and if found valid, resolution.

Claim investigation and the final ruling on validity are beyond the scope of a reporting and referral system and are the purview of legal experts and systems. However, it is important to note that in most systems, claimants are protected from harassment or retaliation—even if their claims are found to be invalid—and this protection should be reflected in the practices of a reporting and referral system.

Data protection in Ukraine—Laws

Collection and processing of personal data while documenting cases of discrimination are regulated by the Law of Ukraine “On protection of personal data.” Under this law, any collection, analysis, or disclosure of personal data must be done for specific and legitimate purposes and is only allowed with consent of the individual whose data is being collected. Use of personal data for historical, statistical, or scientific purposes is permitted only when the data has no personally identifying components. Any database of personal data in Ukraine must be registered in the State Register of personal databases.

Information collected in the process of filing a discrimination complaint is protected under the same laws that govern pre-trial investigations, which limit the disclosure of the facts of the case. Closed court hearings are allowed to prevent the disclosure of information or other intimate aspects of individuals involved in the case and when doing so, is required by the interests of safety of defendants, victims, witnesses, and other persons involved in the case and family members or close relatives.

Use of data to initiate criminal cases

However, if a citizen files any complaint, including a discrimination complaint, and in the process of investigation, inquiry, or trial, there is evidence that the individual committed illegal acts, then a criminal case can be initiated against him/her under the Criminal Procedure Code of Ukraine.²²

Data protection in Ukraine—Existing monitoring/reporting systems

The existing systems in Ukraine for monitoring violation of rights PLHIV and vulnerable populations observe confidentiality in the process of data collection and reporting and limit disclosure of data in case resolution to only those directly involved in the case. Potential claimants are notified of this protection in writing. An example of integration of confidentiality and disclosure requirements into codes of ethics can be found in Annex B from the organization “Gidnist” (Dignity).

Referral systems

International monitoring and reporting systems often incorporate components of the following:

Documentation of informal or internal resolution attempts

Many governmental or anti-discrimination commissions encourage an individual or organization that is considering filing an official complaint to first explore informal resolution options. If an individual has an employer who is discriminatory, it is best to first broach the subject with the manager or the manager’s superior. Or if a client has experienced discrimination in the provision of services, explore if there is a formal complaint system with that service provider. Often organizations will work to resolve these accusations before they become more formalized through external involvement.

However, the process of accessing internal complaint systems must be weighed against additional potential harm. Once the options that are safely within one’s situation are exhausted, then lodging a

²² Direct detection by the inquiry body, investigator, prosecutor, or the court of a crime indication constitutes the grounds for a criminal case (Criminal Procedure Code, Art. 94).

complaint with the more centralized authority will be appropriate. But it is important that the reporting system be able to respond to any requirements for internal resolution before the case is referred to external advocates.

Ability of the claimant to control whether the case is referred for resolution

If a reporting system is designed to facilitate referrals, this must be an option that a claimant has the ability to choose or reject. Claimants must also be made aware of the personal information that will be shared in the context of a referral.

If the reporting system is designed to facilitate referrals, there must also be a mechanism to ensure that referrals do not get lost at the wrong agency. For example, if an organization that receives a referral cannot adequately resolve a person's claim but knows of another organization that can, it should have the ability to refer the claim to the appropriate provider and report back to the reporting system so that there is always an accurate record of where the case is sitting. Also, the person filing the claim should be updated, so that this person does not lose track of the status of his or her claim.

Dual reporting

Sometimes there is need for dual reporting. For example, the human rights authority that receives the claim files it with another parallel organization, such as the agency responsible for employment discrimination, so that they are aware of the case. This courtesy between organizations ensures that the client receives the best care available and also that each organization interested in tracking these cases is aware of them.

Resolution reporting

It is important for the sake of transparency to maintain contact with the client and provide a report of any resolution. Not only will clients feel better about reporting their discriminatory experience if they can feel they have a full understanding of the events and conclusions associated with their claim, but potential claimants will be more likely to report if they can see that previous cases have been resolved.

Managing expectations

An effective reporting system should explain what will happen once a person has filed a discrimination statement, whether anonymous or otherwise. Some organizations commit to responding to a claim within two business days to confirm receipt of the claim. Others are not so exact with their timing, although they promise to respond whether or not they are able to follow through with an investigation. Some organizations assign a number to each claim filed and send this number back to the person who filed the claim so that he or she can track the progress of the complaint. A mechanism for receiving feedback from the organization so that a person can know the status and outcome of the claim is important.

Referral resources in Ukraine

Limited effectiveness of government organizations, judiciary, and law enforcement

While the state judiciary and law enforcement should play the major role in protecting the rights of its citizens, including people living with HIV and representatives of vulnerable groups, local experts in Ukraine agree that this option would be problematic in terms of human rights violations. At the same time, the role of ombudsman (www.ombudsman.gov.ua) in protecting the rights of PLHIV and vulnerable groups is not efficient with limited authority and resources despite a broad mandate.²³ These factors lead to the conclusion that at this point in time in Ukraine, few governmental organizations/systems would be effective for resolving cases of discrimination.

²³ UNAIDS. 2008. *Comprehensive External Evaluation of National Efforts in Response to HIV/AIDS Epidemic in Ukraine: Consolidated Report. Version "0."* Geneva: UNAIDS.

Network of human rights protection NGOs

Among NGOs, which may receive information about cases of discrimination and help settle such situations, there is a network of human rights protecting organizations. In addition, many HIV-service organizations include human rights protection in their scopes of their work, understanding the connection between discrimination and social assistance to people living with HIV and members of vulnerable groups.²⁴

Only a few organizations are primarily involved in monitoring of human rights violations and providing services to vulnerable groups: All-Ukrainian Human Rights Movement “Gidnist” (Dignity); Regional Information and Human Rights Center for Gays and Lesbians “Nash Svit” (Our World); Association of MAT (medical-assisted therapy) Clients; and Mykolaiv Association of Gays, Lesbians and Bisexuals. These organizations have created systems of monitoring violations of human rights and advocacy.

Typically, these organizations use their own resources (staff lawyers, consultants) for the protection of human rights or have agreements (memoranda, agreements) to refer clients to other human rights protection organizations. Information about resolved cases is reported and is available, usually at the organization website. However, such cases are few and are often precedent in nature.

Resource

Reference book of NGOs working in the field of human rights and public interests

www.irf.ua/files/ukr/programs/rol/hr_dovidnyk.pdf

International Conventions and European Court of Human Rights

Ukraine has ratified several international instruments on human rights, and its Constitution provides strong authority to international law defining ratified treaties as national legislation, superseding national law when there is conflict.²⁵ However, experts indicate that during the deliberations in courts of Ukraine, there is no tradition to refer to the international conventions. The major agreements ratified by Ukraine in the field of human rights protection are as follows:

- Universal Declaration of Human Rights
- International Convention on Civil and Political Rights
- International Convention on Economic, Social and Cultural Rights
- International Convention on the Elimination of All Forms of Racial Discrimination
- International Convention on the Rights of Disabled People
- European Convention on Human Rights and Fundamental Freedoms
- Framework Convention on National Minorities’ Protection
- International Convention of the Status of Refugees
- Declaration on Elimination of All Forms of Intolerance and Religious Discrimination
- Convention on Elimination of All Forms of Discrimination against Women
- Convention on the Rights of the Child
- Convention against Discrimination in Education
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
- Minimum Standard for the Treatment of Prisoners
- World Declaration on Ensuring the Survival, Protection and Development of Children,
- Convention on Discrimination in Labor Sector, and others.

Since September 11, 1997, when the Law “On Ratification of the European Convention on Human Rights and Fundamental Freedoms” came into force in Ukraine, the citizens of Ukraine have the opportunity to

²⁴ V. Riabukha, T. Bordunis, and A. Tiutiunyk. 2009. *AIDS-watch: Experience of the Project on Human Rights Monitoring and Protection in the Sector of Response to HIV/AIDS Epidemic*. New York: UNDP; UNDP. 2008. *Challenge and Response: HIV/AIDS and Human Rights in Ukraine*. New York: UNDP.

²⁵ Constitution of Ukraine, Article 9; Law of Ukraine “On International Treaties of Ukraine,” Article 19.

make appeals to the European Court of Human Rights in Strasbourg after all legal options have been exhausted in Ukraine. While the decision of the European Court is not subject to appeal and is binding, there is no data on HIV-related cases that have been taken to the European Court at this time.

Recommendations:

- The efforts to monitor, report, and resolve cases of discrimination in Ukraine need to identify opportunities to support the efficiency and effectiveness of government organizations charged with the protection of human rights.
- Discrimination monitoring, reporting, and referral systems should collect and disseminate information on the effectiveness of government and private sector resources for resolving cases.
- It is important to protect the role of NGOs in monitoring and protecting the rights of citizens.

Reporting of aggregated data

Implementers of discrimination monitoring systems should make an effort to provide the data to the public and to use it to create new policies, public information campaigns, and trainings to reduce regional or national stigma and discrimination levels. If a case reporting system is established, as described above, aggregated data on cases filed must be reported in a non-identified way.

Designers of a reporting system should decide if their data will be reported as part of an existing formal reporting process or used to provide an additional point of information in contrast to formal reports (otherwise known as shadow reporting—described below). In either case, understanding the data that is needed for these reports will be crucial in designing the reporting system. For example, gender and age are almost always integral to reports and should be collected on case reporting forms.

Shadow reports

A method of gauging social disparity is to encourage the submission of shadow reports. A shadow report is information submitted by nongovernmental organizations to monitoring bodies to address omissions, deficiencies, or inaccuracies in the official government reports. The shadow reporting process plays a central role in holding governments accountable to their obligations.²⁶ These reports can provide perspective, either anonymously or not, to governing and monitoring bodies. They can provide unofficial insight into the reality of the situation from the perspective of the public.

Protection of Confidentiality in Data Reporting

After case data is de-identified, special attention will need to be paid to cell size—for example, if a case from a female drug user, age 18, who is an ethnic minority, is reported for a small town, this information may be enough to identify the claimant. It is helpful to set a standard minimum cell size for data reporting—depending on the number of potentially identifying characteristics disclosed.

If a cell has less than the minimum cases should be combined with other cases at a higher level of reporting to make the defining characteristics of the case less identifying; in the example above, reporting on total cases among PWID in an oblast.

²⁶ Global Rights Partners for Justice. 2009. *Guide to Shadow Reporting: Using the International Covenant on Civil and Political Rights to Protect the Rights of LGBTI Persons*. Available at: www.globalrights.org/site/DocServer/Guide_to_Shadow_Reporting_July_2009.pdf?docID=10544.

Discrimination data reporting in Ukraine

A number of regulations in Ukraine²⁷ contain provisions aimed at preventing the causes of discrimination of PLHIV and members of vulnerable populations. However, none of the regulations contain mechanisms for the documentation and registration of the cases of stigma and discrimination against PLHIV and vulnerable groups.

Nongovernmental organizations that collect information on violations of rights of PLHIV and representatives of vulnerable groups [such as the Network of PLHIV, and Regional Information and Human Rights Center for Gays and Lesbians “Nash Svit” (Our World)] have experience presenting this information to the ombudsman reports and international organizations or foreign governments including the United Nations for development of the Universal Periodic Report on human rights worldwide, to the U.S. State Department Human Rights Report (www.state.gov/j/drl/rls/hrrpt/index.htm), and to the Council of Europe Monitoring Committee. Alternative reports prepared by international or nongovernmental organizations are not part of the government reporting system, but they are used in formulation of policy and services, such as the shadow report on the Convention on the Rights of the Child in Ukraine.

Along with efforts to continuously monitor human rights violations, periodic research is conducted in Ukraine that provides information for analyzing stigma among people living with HIV and vulnerable groups.

- Results of a stigma assessment in Ukraine in 2005 found that the percentage of people tolerant to HIV-positive people was 0 percent in youth (15–24 years old) and 2 percent in adults (25–49 years old).²⁸ Unfortunately, tolerance indicators have not been subsequently measured in Ukraine since officials determined that the measurement indicators were not relevant for the country.²⁹
- In 2011, for the first time, Ukraine implemented the “PLHIV Stigma Index” under support of the Global Network of Positive People. This study documented the situation of both external and internal stigma for PLHIV.
- Similar studies have been conducted by other communities, including the lesbian, gay, bisexual, transgender (LGBT) community (One Step Forward, Two Steps Back: LGBT Situation in Ukraine in 2010–2011).

²⁷ Law of Ukraine “On response to transmission diseases caused by the Human Immunodeficiency Virus (HIV) and legal and social protection for people living with HIV” and the National Program for HIV-infection prevention, treatment, care and support of HIV-infected and people with AIDS in 2009–2013.

²⁸ National Report on Implementation of the Declaration of Commitment on HIV/AIDS (Reporting Period: January 2004–December 2005).

²⁹ That was the following question: Should a member of your family be infected with HIV, would you keep it a secret? National Report on Implementation of the Declaration of Commitment on HIV/AIDS (Reporting Period: January 2004–December 2005).

Status of Discrimination in Ukraine

Report on the implementation of the project “Scaling up human rights monitoring network in the context of HIV/AIDS response in Ukraine” Kyiv–2010

gidnist.com.ua/index.php?area=1&p=static&page=proj2

The report reflects the PLWH human rights situation in ten oblasts of Ukraine. It contains data on human rights violations by oblast and sector (healthcare sector, law enforcement agencies, education, other). The report also provides information on the number and types of legal services provided.

“One step forward, two steps backward: Status of LGBT in Ukraine in 2010–2011” Kyiv–2011

www.gay.org.ua/publications/report2011-1-u.pdf

The publication contains information on the analysis of legislation from the LGBT point of view, the level of homophobia in society, as well as the analysis of data on the violation of LGBT rights in various sectors: law enforcement agencies, labor, education, social field, information, communication with general public, and healthcare. In addition to the description of the status of the use of generalized digital data, the publication contains an analysis of cases of the violation of rights and freedoms on the basis of hatred toward LGBT in 2010/2011.

It should be noted that such studies do not provide for a service delivery mechanism and/or referral of such cases to resolution.

Recommendations:

- Data from discrimination monitoring and referral systems should be made available and coordinated with national and international NGO sector reporting opportunities.
- Any disaggregation of data must not inadvertently disclose personally identifying information.
- Opportunities should be identified to use discrimination data to reinforce and triangulate data on stigma and human rights.

SYSTEM SCOPE

There are three points of discussion regarding the scope of the reporting system: inclusion of stigma and/or discrimination, PLHIV and/or other key populations, and the sectors covered by the system (e.g., healthcare, employment, etc.).

Stigma and/or Discrimination

Most reporting systems around the world focus on reporting cases of discrimination, since discrimination is actual behavior that is easier to document and resolve according to local laws. Reporting cases of stigma, or attitudes, is more difficult and may prove challenging for documentation and resolution.

There are also overlapping, not completely identical, issues between discrimination and violations of human rights. For example, a country's procurement system may be insufficient to guarantee a consistent supply of critical medications, resulting in a violation of the human right of access to healthcare. This in and of itself is not a case of discrimination. However, if healthcare workers in a country refuse to provide medications to people who inject drugs (PWID) who are HIV positive solely on the criteria of active drug use, this barrier to healthcare would be a case of discrimination.

The existing systems in Ukraine are primarily focused on reporting cases of violations of rights and cases of discrimination. One organization, the Regional Information and Human Rights Center for Gays and Lesbians "Nash Svit" (Our World), documents cases of humiliation and threats on the basis of actual or perceived sexual orientation providing information on stigma in general daily life.

Multiple organization-specific systems of monitoring violations of rights of PLHIV and key populations exist in Ukraine:

- All-Ukrainian Human Rights Movement "Gidnist" (Dignity)
- Regional Information and Human Rights Center for Gays and Lesbians "Nash Svit" (Our World)
- Association of MAT Clients, the Association of Ukrainian Monitors of Human Rights in the Law Enforcement Sector
- All-Ukrainian League "Legalife"
- Mykolayiv Association of Gays, Lesbians, and Bisexuals
- Association MAT Clients in Ukraine

Some of these organizations are just beginning to create their own systems for monitoring human rights violations and discrimination, often with a focus on a specific population [PWID, representatives of the LGBT community, sex workers (SWs), etc.] or sector (law enforcement, medicine, etc.). There is no

comprehensive or collaborative structure that directs the design and reporting of information from these individual systems.

Stigma Indexes

If there is interest in quantifying and reporting on stigma, there are several resources to help stakeholders provide a framework for gauging current stigma levels in a specific region or country.

The People Living with HIV Stigma Index (www.stigmaindex.org) is a result of a partnership between several high-profile organizations including the International Planned Parenthood Federation, Joint United Nations Programme on HIV/AIDS (UNAIDS), International Community of Women Living with HIV (ICW), and Global Network of People Living with HIV (GNP+). Since 2004, these partners have led a broad consultation process, and the final comprehensive tools they have made available build on existing work by numerous organizations and specialists in index design. The index questionnaire and user's guide have been tested and piloted by PLHIV networks in India, Kenya, Lesotho, South Africa, Trinidad and Tobago, China, Thailand, and the United Kingdom.

The People Living with HIV Stigma Index³⁰ has produced a comprehensive survey, designed to be administered by people living with HIV to other people living with HIV, in order to effectively gauge stigma and discrimination within all areas of a person's life. Areas addressed in the index include indicators focusing on living with HIV, internal stigma, human rights, HIV testing, disclosure, and the provision of healthcare. The initiative encourages any national partnership interested in "rolling out" the survey to include PLHIV in every step of the process to ensure the proper perspective is represented and that the data being collected are of the highest quality.

However, it should be noted that the PLHIV Stigma Index does not specifically capture the experience of key populations [such as males who have sex with males (MSM), PWID, and SWs], aside from experiences related to their HIV status. The terms MSM and SW are mentioned within the Stigma Index's definitions, and MSM, PWID, and SWs are cited as populations that should be included within the referral system of a discrimination reporting system. However, there is no information or section specifically tailored to the needs of these key populations.

While there are no formal stigma indexes for key populations, there is supplementary material on the Stigma Index website, which can provide insight and points to consider. These articles include "Strengthening Work with MSM in Africa"³¹ and "Stigma: A Stumbling Block to Essential Services," in which the double stigma of being a PLHIV and an MSM/PWID/SW is discussed.³²

³⁰ The People Living With HIV Stigma Index. Available at: www.stigmaindex.org.

³¹ People Living with HIV Stigma Index. *Strengthening Work with MSM in Africa*. Available at: www.stigmaindex.org/42/feature-articles/strengthening-work-with-msm-in-africa.html.

³² People Living with HIV Stigma Index. *Stigma: A Stumbling Block to Essential Services*. Available at: www.stigmaindex.org/39/feature-articles/stigma-a-stumbling-block-to-essential-services.html.

Recommendation:

- The reporting, monitoring, and referral systems in Ukraine should focus on cases of discrimination. Reporting and monitoring of stigma is more appropriate for regular population-based surveys and periodic research.

PLHIV and/or Key Populations

While the inclusion of HIV status, sexual orientation, drug dependency, and sex work as covered bases in a country's anti-discrimination codes will certainly make reporting and resolution of stigma and discrimination cases for these populations easier, the absence of these protections does not necessarily mean that they should be precluded from a reporting system that documents cases of stigma and/or discrimination. It just might mean more limited local resources for resolving discrimination cases. In the absence of formal discrimination protections and resolution resources, it may be helpful to consider integrating discrimination reporting into other existing human rights-based systems.

Recommendations:

- Discrimination monitoring, reporting, and referral systems in Ukraine should be inclusive of PLHIV and members of key populations.
- Data should be disaggregated by population.

Sectors

While much of the focus of stigma and discrimination related to HIV status is on the health sector, HIV-related stigma can be documented in almost every aspect of life, including housing, employment, receipt of government services, access to education, etc. In Ukraine, NGOs that monitor violations of rights of PLHIV and vulnerable groups, monitor violations of rights of a specific vulnerable group with which they work and/or to which they belong or in a clearly defined sector. Most often this is limited to the public healthcare sector and the performance of law enforcement agencies.

Recommendations:

- Because of the overwhelming scale of discrimination and the direct impact on HIV-related morbidity and mortality, discrimination monitoring, reporting, and referral systems in Ukraine should primarily focus on issues of healthcare and law enforcement sectors.
- Discrimination monitoring, reporting, and referral systems should not reject cases of discrimination in other sectors when they arise.
- Opportunities should be identified to engage other sectors (e.g., education, labor, housing, etc.) in systemic monitoring, reporting, and resolving cases of HIV-related discrimination.

TECHNICAL SOLUTIONS

The last decade has witnessed unprecedented advances in the way that information is solicited, collected, visualized, and disseminated using the internet and wireless technologies. The advent of crowdsourcing and data visualization, in particular, have advanced thinking about the ways citizens can hold government

and the private sector accountable for the delivery and quality of services and about raising awareness and mobilizing citizens to address problems confronting their communities.

The technical solutions and design of a reporting system will depend on the parameters, functions, and priorities of the system. For example, the technical approach for a component of a system that is primarily designed to capture index/survey data will look very different from components that are primarily designed to capture and refer case reports.

Relatively simple, open source software exists to create an online platform that can house and visualize real-time data on incidents of discrimination against PLHIV across Ukraine; serve to consolidate historical information, such as indexes, surveys, and polls; and increase the comparability of data. However, when identifying and applying technical solutions for the reporting system, the primary concerns must be accessibility for potential claimants and effective reporting of data. Other considerations must be taken for implementation efficiency and sustainability.

Data Collection

Active data collection

Collecting data by seeking personal accounts and perspectives either for case reporting or index surveys.

Passive data collection

Collecting data that are brought to the system through a claimant or third party advocate such as case manager or lawyer.

The primary mechanism of data collection in Ukraine is passive data through NGO representatives or websites. This process usually takes the form of individuals documenting cases of discrimination through web-based submission of standardized forms for the organization. While this is most often initiated by the individual who has experienced the discrimination, there are cases where individuals are approached to provide information on a case that they have not reported. Systematic active data collection has only been used during the implementation of the PLHIV Stigma Index and isolated studies of LGBT communities.

Reporting Mechanisms

There are many ways an individual or group can report an incident or series of incidences. Some organizations provide a form to be completed and submitted via email, mail, or fax.³³ If there is no official form, it is possible to call the organization to gain information or make an official claim. Some organizations only allow filing claims in person or via mail.³⁴ No matter what method of reporting preferred by the organization, be it phone, fax, email, mail, text, or in person, it is important that all claim submission methods be explained. If the individual or organization filing the claim has questions, there should also be an explanation of possible ways to get this question answered.

To date, discrimination monitoring, reporting, and referral systems have been designed and implemented by individual NGOs without a common structure for collecting, consolidating, or reporting data. While there is recognition of the need for such a structure, the cadre of NGOs currently working with PLHIV in

³³ Anti-Discrimination Commission of Queensland Complaint Form. Available at: www.adcq.qld.gov.au/main/complaints_inclvideo.html; Mason City, Iowa Complaint Intake Form. Available at: www.masoncity.net/pView.aspx?id=1309&catid=58.

³⁴ U.S. Equal Employment Opportunity Commission. *How to File a Charge of Employment Discrimination*. Available at: www.eeoc.gov/employees/howtofile.cfm.

Ukraine do not share a common vision of the structure or agree how to incorporate current web-based and mobile technology into the structure.

Crowdsourcing and Mapping (crowdmapping)

Crowdsourcing is the process in which an organization or individual uses web-based and wireless technology to solicit data, information, and feedback on a project or initiative from any other person, regardless of their physical location. Data are submitted through the web, SMS, MMS, and Tweets.

Data visualization employs web-based databases and design tools to manipulate, analyze, and present data in a user-friendly format. Mapping is a data visualization technique where crowdsourced or other data are assigned reference points (like a dot or triangle) and placed on an online dynamic map, like Open Street Map (www.openstreetmap.org) or Yandex Maps (www.maps.yandex.ru). Users sort and filter data with clicks of a mouse, zooming in and out of the map to display quantities, trends, and hot spots of occurrences on a national, regional, and local basis.

Crowdmapping has gained popularity for facilitating crisis response (haiti.ushahidi.com) and increasing citizen participation in electoral monitoring (www.kartanarushenyi.org). It has also been deployed to address issues such as sexual harassment (harassmap.org) and to stimulate local infrastructure repair (www.ukryama.com). Crowdmapping platforms continue to evolve into multi-function online resources where, in addition to data being captured and visualized, actionable information like legal analysis and referrals and links to international and local support networks is provided for specific target groups. The platforms also house blogs and topical discussion forums and links to relevant research and historical data.

Crowdmapping software is free for download through open source providers, such as crowdmap.com. Modifying the platform and building a website to house other data and functions will require technical know-how, though the availability of skilled programmers in Ukraine will keep costs low and quality/reliability high. The software is flexible and adaptable; it can be embedded into a Ukrainian NGO's website or launched as a stand-alone resource, and platform users may be kept anonymous. Security is a crucial component of platform deployment, particularly when platform users will have major concerns about privacy and anonymity. Since crowdsourcing platforms are just beginning to be used in Ukraine, international consulting in online security may be warranted to ensure that data housed in a discrimination monitoring platform are protected.

While the health sector has embraced the use of wireless technology as a tool, for example, to monitor and facilitate patient adherence to tuberculosis treatment regimes, it has yet to embrace the application of crowdsourcing to engage unique target groups like PLHIV, address discrimination, and raise awareness of stigma.

Ukraine Opportunity

The initiative to develop a stigma and discrimination monitoring system in Ukraine is a unique opportunity to pilot an integrated crowdsourcing platform that (1) serves as a resource to PLHIV on their rights, legal recourse, and how to access support networks when confronting discrimination; (2) consolidates Ukrainian NGO discrimination monitoring and referral approaches under one umbrella; (3) provides both real time and historical data on incidences of discrimination in Ukraine, and (4) provides access to indexes and other comparative international data on stigma and discrimination. However, a number of formidable challenges must be taken into consideration:

- **Privacy.** PLHIV may perceive participation in the platform as a privacy risk. Platform users must be guaranteed anonymity—whether it’s an NGO, lawyer, or person living with HIV reporting a discriminatory incident.
- **Security.** There is a dearth of Ukrainian programmers experienced in securing a platform against online attacks and hackers. International expertise will be required to adequately secure the platform.
- **Internet penetration.** Current estimates put Ukrainian internet penetration at 40 percent; however, it is assumed the percentage is much lower in rural areas. Awareness must be raised of the possibility to report incidents offline to NGOs or to a call center operated exclusively for the platform.
- **NGO cooperation.** Ukrainian NGOs will have to agree on who will take ownership of design and implementation (in the short and long term) of the platform. More importantly, NGOs will have to agree on a common approach to reporting and cataloging incidents and advising PLHIV on referral.
- **Promotion and outreach.** Creating buy-in for use of the platform by PLHIV will require a substantial, targeted strategic communications effort.

Recommendations:

- Discrimination monitoring, reporting, and referral systems need to be inclusive of both passive and active data collection.
- Opportunities to develop and pilot a common data collection and reporting platform should be explored.
- Mechanisms for reporting need to incorporate web-based, wireless, and offline channels (such as web, phone, in person, by third party) to increase accessibility.
- Maintaining privacy/anonymity for platform users is paramount to ensuring platform credibility and usability.
- A plan to address platform security should be devised in the early stages of planning for platform rollout.

SOURCES OF FUNDING

All existing systems for monitoring violations of PLHIV rights in Ukraine are funded by international donors, which appear to be the only feasible source of support for the near future. Experts believe that funding from the state or local budgets is impossible due to lack of funding for NGOs in general and government agencies’ lack of interest in financing a structure that provides oversight. While funding and location of a monitoring system within government is the most sustainable long-term solution, stakeholders have expressed concern about the current viability and effectiveness of the structures that exist.

Recommendations

- In the short term, donor funding appears to be the most viable source of financial and technical support for discrimination monitoring, reporting, and referral systems.

- Donor-funded activities should incorporate capacity-building and technical assistance components to increase the effectiveness of government agencies charged with the protection of human rights in Ukraine.

PROMOTION OF REPORTING SERVICES

The public must be made aware that they can report discrimination and are encouraged to do so. There must also be a way to promote specific reporting structures and processes. This could be in the form of trainings of officers, health workers, and other civil servants who might work closely with potential victims of harassment or discrimination, requirements for posting of information on individual rights, and specific outreach and communication among marginalized populations.

In Ukraine, the State does not promote systematic awareness of citizens about their rights and possible procedures for access to appeal. The key source of information on rights for marginalized populations are NGOs.

Under the law in Ukraine, ignorance of the law does not exempt from responsibility. And while professionals such as doctors, teachers, social workers, judges, and law enforcement representatives are familiarized with the standards and requirements of legislation and regulations related to their professional performance and discrimination protections, such awareness building is extremely poor, as evidenced by the consistent and systematic violations of the rights of HIV-positive individuals or members of vulnerable populations. In the opinion of experts, these violations stem from not only stigmatization but also professionals' ignorance of the law.

Recommendation:

- Any activity to monitor, report, or resolve cases of discrimination must include a public awareness component, especially targeting marginalized populations who will be less likely to access such resources.

ANNEX A: STIGMA AND DISCRIMINATION REPORTING SYSTEMS

Anti-Discrimination Commission Queensland—Australia

As the website states: The Anti-Discrimination Commission Queensland (ADCQ) (www.adcq.qld.gov.au) is an independent statutory authority established under Australia’s Anti-Discrimination Act 1991. Its core business mission is to receive and deal with complaints of discrimination and other contraventions of the Act, and to promote human rights in Queensland. It has offices in Brisbane, Rockhampton, Townsville and Cairns.

The ADCQ is a case reporting system in which a complaint form is downloadable on its website. The form asks for personal information and details about the company or individual against which the complaint is being filed. These details include the location and nature of the incident. The form states that a person wishing to issue a complaint anonymously can ask for an associate/family member to file for him or her. It states that if anonymity is not requested, the client’s details will be sent to the accused as notice of the filed claim to all parties involved.

The ADCQ publishes several resources including human rights information for Aboriginal and Torres Strait Islander Peoples, LGBT and intersex (LGBTI) communities, Muslim communities, racial and religious hatred, youth, and sexual harassment. The ADCQ is also associated with the “It’s Okay to Complain” website (www.complaints.qld.gov.au), which is a joint initiative of the independent agencies responsible for handling complaints in Queensland, Australia.

Jamaica National HIV-Related Discrimination Reporting and Redress System—Jamaica

The Jamaica National HIV-Related Discrimination Reporting and Redress System is supported through the Global Fund to scale up HIV prevention, treatment, and policy efforts in Jamaica. This is a national system under the supervision of the National HIV/STI Program. Since 2007, its development has been guided by a Multisectoral Advisory Group including advocacy groups, government sectors, and PLHIV. The system is the policy/advocacy component of the national response to HIV/AIDS articulated in the National Strategic Plan 2002–2006 and expanded to the Enabling Environment and Human Rights Program (National Strategic Plan 2007–2012).

Through the Jamaican Network for Seropositives (www.jnplus.org), people can file a complaint using an online form that asks for details about the incident and the accused individual or organization. It can be completed by, or on behalf of, anyone who believes he/she has experienced or witnessed HIV-related mistreatment, abuse, or discrimination, regardless of his/her HIV status. Once submitted, this information will be handled in a secure, confidential manner by trained officers. Statistical information may be shared with national or regional monitoring agencies, but personal or identifying information will be kept strictly confidential.

Care Quality Commission—United Kingdom

The United Kingdom-based Care Quality Commission (CQC) (www.cqc.org.uk) is an independent regulator focusing on checking whether hospitals, care homes, and care services are meeting government standards. Funded by the government, the CQC began operating on April 1, 2009, as the independent regulator of health and adult social care in England. Its establishment replaced three earlier commissions:

the Healthcare Commission, the Commission for Social Care Inspection, and the Mental Health Act Commission.

The CQC website provides a comprehensive step-by-step explanation of the complaint process and outlines the procedures depending on whether a person is complaining about social care or healthcare and whether the care is paid for by public funds or the individual has paid for it. Depending on the answers to these questions, there are several different organizations to which the CQC can refer an individual. All organizations—including hospitals and services, independent hospital services, mental health services, and social services—are listed with contact information.

Equal Employment Opportunity Commission—USA

This U.S. federal organization protects against employment discrimination. The EEOC (www.eeoc.gov) operates a Case Reporting System and publishes statistics regarding cases it has received and brought to litigation on its website. The EEOC enforces the protective employment and human rights laws that exist within the United States. Its online resources explain the process for filing a complaint as a non-federal employee, a federal employee, and a job applicant.

There is a time limit for anyone wishing to file a formal complaint, and the parameters are clearly stated on the website. The EEOC will most likely encourage *mediation* first and then work with the client regarding further steps if this is unsuccessful. An online assessment tool is available to gauge whether the EEOC is the appropriate agency to ask for help. However, there is no mechanism for filing charges online. All charges are received in person at one of the 53 EEOC offices nationwide. The client can also file a charge through the mail or can start the process over the phone.

Stigma Index—Multilateral

The People Living with HIV Stigma Index (www.stigmaindex.org) is an indicator reporting system that aims to measure levels of HIV stigma in the workplace, health system, educational system, and in general. The index is a collaboration of several professional organizations including the International Planned Parenthood Federation, UNAIDS, ICW, and GNP+.

The Stigma Index Questionnaire has been tested and piloted by PLHIV networks in India, Kenya, Lesotho, South Africa, Ukraine, and Trinidad and Tobago. The questionnaire is not available on the website, but the User's Guide provides answers to questions about stakeholders, implementation, training, and data reporting.

Health Care Workers Stigma Index—Multilateral/Futures Group

Futures Group is creating a survey that will be used as an indicator reporting system of stigma against HIV-positive patients and employees in healthcare settings. The information obtained in the study will be used to offer practical guidelines to hospitals and hospital staff who provide care for people living with HIV, so that needs of both hospital staff and patients can be met. The questionnaire is anonymous, and participants are not asked to give their name. In this way, complete honesty and candor are encouraged.

Types of indicators present in the study include coworkers' behavior toward HIV-positive or perceived HIV-positive patients and other coworkers. There are also questions focusing on perceived danger or changed behavior in carrying out various health procedures for HIV-positive or perceived HIV-positive patients. The issues of confidentiality, training, and moral judgment are also present throughout the survey.

ANNEX B: CODE OF ETHICS FOR SPECIALISTS MONITORING HUMAN RIGHTS VIOLATIONS—NGO “GIDNIST” (DIGNITY)

1. As a member of the project professional team/project manager, I will consider/put clients and their families' interests above other interests.
2. In my work I will treat clients humanely, fairly, and impartially irrespective of race, religion, nationality, age, sexual orientation, health status, and drug use.
3. I will not inflict deliberate psychological or physical harm on clients, will not insult their human dignity by way of criticism or derision, or with my own ideas, will not endanger clients' life and health or allow other workers to act in such a fashion.
4. I will treat clients with courtesy, encouraging them to change their life for their own benefit and interests.
5. I will address issues and provide services within the scope of my competence.
6. I will not establish sexual, financial, or personal relationships with clients in as much as such actions may be construed as exploitation of a client for personal advantage.
7. I will not exercise my authority with clients for personal advantage.
8. I pledge not to disclose information about others or former clients and their families to anybody with the exception of the project team members.
9. In my personal use of alcohol or psychotropic substances, I will take a responsible attitude toward clients and project team members.
10. I will care for my clients and project colleagues and will actively preempt and eliminate problems resulting from unethical conduct toward clients or team members.
11. I will continue my education and improve my skills and abilities for the purpose of increasing my proficiency and enhancing the quality of services for PLHIV.

ANNEX C: ORGANIZATIONS THAT MONITOR THE VIOLATIONS OF HUMAN RIGHTS OF PLHIV AND KEY POPULATIONS IN UKRAINE

No	NGO	Target groups	Geography	Case Referral	Data Collection Mechanism
	Regional informational and human rights center for LGBT "Nash Svit"	LGBT	Ukraine	Yes (upon the complainant's wish)	Website, Phone
	All-Ukrainian human rights movement "Gidnist"	PLHIV, Key populations	Ukraine	Yes (upon the complainant's wish)	Website, through the representatives of the organization
	Association of MAT clients	PWID who are MAT program clients	Ukraine	Yes (upon the complainant's wish)	Phone, e-mail, fax
	All-Ukrainian League "Ligalaif"	SWs (harassment by law enforcement representatives)	Short-term pilot project covering Kirovohrad, Kyiv	Yes (upon the complainant's wish)	Through the representatives of the organization
	Mykolaiv association of gays, lesbians and bisexual people	LGBT	Mykolaiv	Yes (upon the complainant's wish)	Website, Phone

ANNEX D: STIGMA AND DISCRIMINATION MONITORING SYSTEM DESIGN WORKSHOP ATTENDEES

November 14, 2011 and February 21, 2012

	Full name	Organization	Position	Contact information (email, phone)
1	Andrushchak Lidia	UNAIDS	Social Mobilization and Partnership Adviser	andrushchakl@unaids.org 050 4436779
2	Sherstyuk Olena	UNAIDS	Leadership and Advocacy Adviser	SherstyukO@unaids.org 050 351 7821
3	Davis Olena	Coalition of HIV Service Organizations	Chair	davis@hiv.org.ua 067 504 96 75
4	Rokitska Oksana	Center of Social Expertise	Sociologist	oksana.rokitskaya@ukr.net 096 759 44 02
5	Bliakharkyi Yaroslav	All-Ukrainian Network of PLHIV	Officer, PR and Advocacy Team	yarik@network.org.ua 067 440 69 12
6	Lytvyn Sofia	International Organization of Labor	Consultant on HIV/AIDS Stigma in Health Sector	Sofia_lytvyn@ukr.net 050 334 98 87
7	Ilitskiy Aleksei	UNAIDS	M&E Adviser	ilitskia@unaids.org 050 350 98 76
8	Ryzhkov Kostiantyn	Charity "Gidnist"	Consultant on PR, M&E	kryzhrov@gmail.com 063 43 20022
9	Bordunis Tetiana	Charity "Gidnist"	President	bordunis@gidnist.co.ua 067 875 6443
10	Hroza Aliona	Charity "Gidnist"	Manager	alena@gidnist.com.ua 063 237 64 77
11	Mykolenko Volodymyr	Ukrainian Foundation of Legal Support	Coordinator	mykolenko.w@gmail.com 050 442 36 65
12	Pavlenko Paola	USAID	Senior AIDS Adviser	ppavlenko@usaid.gov 050 448 62 58
13	Kucheruk Olena	International Renaissance Foundation	Public Health Program	kucheruk@irf.kiev.ua 050 38 34413
14	Boiko Alla	USAID HIV/AIDS Service Capacity project	Civil Society Development Manager	a.boyko@uscpc.kiev.ua 067 788 18 41

Designing an Effective HIV Discrimination Monitoring, Reporting, and Referral System

	Full name	Organization	Position	Contact information (email, phone)
15	Beardsley Kip	Health Policy Project	Technical Adviser	kbeardsley@futuresgroup.com 202 777 9752
16	Wild Christopher	U-Media Project	Chief of Party	cwild@internews.org 380 67 224 8993
17	Gordeiko Vladimir	UNDP	Project Manager	Vladimir.gordeiko@undp.org 095 28 28 086
18	Dovbakh Hanna	International HIV/AIDS Alliance in Ukraine	Associate Director: Policy and Partnership Regional Technical Support Hub Director	dovbakh@aidsalliance.org.ua 050 4426989

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