UNAIDS 2014 | GUIDANCE NOTE

Reduction of HIV-related stigma and discrimination

Resource kit for high-impact programming

This Guidance Note is part of the resource kit for high-impact programming that provides simple, concise and practical guidance on key areas of the AIDS response. The resource kit is jointly developed by the Joint United Nations Programme on HIV/AIDS. The resource kit can be accessed at http://www.unaids.org/en/ourwork/programmebranch/ countryimpactsustainabilitydepartment/globalfinancingpartnercoordinationdivision/

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The development of this Guidance Note was led by the United Nations Development Programme (UNDP) and the UNAIDS Secretariat. This Guidance Note provides simple, concise and practical guidance on addressing aspects of HIV-related stigma and discrimination in national AIDS responses. References and links to full guidance are provided in the last section of the Guidance Note.

WHAT IS NEW?

Key resources have recently been made available, including the following:

- The People Living with HIV Stigma Index research methodology and reports from more than 50 countries (www.stigmaindex.org, www.gnpplus.net).
- Key programmes to reduce stigma and discrimination and increase access to justice in national HIV responses. Geneva: Joint United Nations Nations Programme on HIV/AIDS; (http://www.unaids.org/en/media/unaids/ contentassets/documents/document/2012/Key_Human_Rights_Programmes_en_ May2012.pdf, accessed 16 December 2013).
- HIV and the law: Risk, rights and health, New York, Global Commission on HIV and the Law, July 2012 (http://www.hivlawcommission.org/index.php/report, accessed 16 December 2013).

In addition, an improved indicator to measure discriminatory attitudes in the general population has been included in the Global AIDS Response Progress Reporting (GARPR) core indicators.¹

¹ World Health Organization, Joint United Nations Programme on HIV/AIDS, United Nations Children's Fund. Global AIDS response progress reporting 2014: Construction of core indicators for monitoring the 2011 United Nations Political Declaration on HIV and AIDS. Geneva: Joint United Nations Programme on HIV/AIDS; 2014, (http://www.unaids.org/en/ media/unaids/contentassets/document/2014/GARPR_2014_guidelines_en.pdf).

Introduction

Stigma and discrimination are among the foremost barriers to HIV prevention, treatment, care and support. Specifically, research has shown that stigma and discrimination undermine HIV prevention efforts by making people afraid to seek HIV information, services and modalities to reduce their risk of infection and to adopt safer behaviours lest these actions raise suspicion about their HIV status. Research has also shown that fear of stigma and discrimination, which can also be linked to fear of violence, discourages people living with HIV from disclosing their status even to family members and sexual partners and undermines their ability and willingness to access and adhere to treatment. Thus, stigma and discrimination weaken the ability of individuals and communities to protect themselves from HIV and to stay healthy if they are living with HIV.

Box 1. Definitions of stigma and discrimination

HIV-related *stigma* refers to the *negative beliefs*, *feelings and attitudes* towards people living with HIV, groups associated with people living with HIV (e.g. the families of people living with HIV) and other key populations at higher risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people.

HIV-related *discrimination* refers to the *unfair and unjust treatment (act or omission)* of an individual based on his or her real or perceived HIV status. Discrimination in the context of HIV also includes the unfair treatment of other key populations, such as some social contexts, women, sex workers, people who inject drugs, men who have sex with men, transgender people, people in prisons and other closed settings and, in some social contexts, women, young people, migrants, refugees and internally displaced people. HIV-related discrimination is usually based on stigmatizing attitudes and beliefs about populations, behaviours, practices, sex, illness and death. Discrimination can be institutionalized through existing laws, policies and practices that negatively focus on people living with HIV and marginalized groups, including criminalized populations.

All country and regional consultations on universal access to HIV prevention, treatment, care and support held in 2010–2013 identified stigma and discrimination as key obstacles to universal access. To that end, the UNAIDS Programme Coordinating Board emphasized that "programmes to reduce HIV-related stigma and discrimination and to increase access to justice should be seen as integral and essential to every national AIDS response, and fundamental to the successful achievement of the goals and activities articulated in HIV strategies, plans and funding proposals" (June 2010 Programme Coordinating Board Report, paragraph 50). The broader socio economic impact of discrimination on employment, education, health, justice and community settings are important aspects that should be an integral part of the response, as stressed by the 31st meeting of the UNAIDS Programme Coordinating Board in its Thematic Segment on Non-Discrimination. Similarly, the Global Fund to Fight AIDS, Tuberculosis and Malaria's (Global Fund) Technical Review Panel has consistently expressed the importance of focusing on human rights and increasing programming to address HIV-related stigma and discrimination.

Within the 2011 United Nations Political Declaration on HIV and AIDS, Member States committed to "national HIV and AIDS strategies that promote and protect human rights, including programmes aimed at eliminating stigma and discrimination against people living with and affected by HIV, including their families ... [and] to promoting laws and policies that ensure the full realization of all human rights and fundamental freedoms for young people, particularly those living with HIV and those at higher risk of HIV infection, so as to eliminate the stigma and discrimination they face" (paragraphs 80 and 83).

Box 2. The Global Fund and human rights

In line with international human rights obligations and the Global Fund's strategic objectives on human rights, impact and value for money, applicants through the Global Fund's New Funding Model are strongly encouraged to incorporate human rights programming in their concept notes. The Global Fund recommends that applicants:

- identify human rights barriers to accessing health services;
- design all health services using a human rights-based approach;
- invest in programmes that remove human rights barriers to accessing services;
- invest in community system strengthening.

This Guidance Note is designed to assist countries in addressing aspects of HIV-related stigma and discrimination in national AIDS responses through political initiatives, using people living with HIV and other key populations (defined in Box 3) as a resource against stigma and, most importantly, costing, budgeting and implementing sufficient stigma-reducing programmes in national AIDS responses, including through the concept note development processes for submission to the Global Fund.

1. Key elements

The UNAIDS Investment Framework explicitly supports the inclusion of programmes that aim to eliminate stigma and discrimination against people living with and affected by HIV, especially for women, children and other key populations. Within national AIDS responses, such programmes serve as critical enablers.

Box 3

UNAIDS in its 2011–2015 Strategy defines key populations as follows:

"Key populations, or key populations at higher risk, are groups of people who are more likely to be exposed to HIV or to transmit it and whose engagement is critical to a successful HIV response. In all countries, key populations include people living with HIV. In most settings, men who have sex with men, transgender people, people who inject drugs and sex workers and their clients are at higher risk of exposure to HIV than other groups. However, each country should define the specific populations that are key to their epidemic and response based on the epidemiological and social context."

Key components of planning for and designing programmes to reduce HIV-related stigma and discrimination include the following steps:

- Identifying in the analysis of the epidemic and response the extent to which HIV-related stigma and discrimination block the provision of services and the demand for services beyond and within health-care settings.
- Identifying who is most affected by stigma and discrimination and planning programmes that will address their particular needs and contexts.
- Costing and budgeting for programmes to reduce stigma and discrimination since many planned programmes are never funded nor implemented.
- Implementing programmes to reduce stigma and discrimination as critical enablers in order to ensure full access to and uptake of evidence-informed "basic programmes".
- Monitoring and evaluating the impact of the programmes.

In order to achieve greater impact, programmes to reduce stigma and discrimination need to take into account the following important aspects:

- The inclusion of people they intend to serve—including people living with HIV, women and girls and key populations—in the design, implementation and monitoring of such programmes.
- Programmes to reduce stigma and discrimination targeted to different sectors, including in families, communities and institutions (e.g. health-care settings and the workplace) with the engagement of multiple target audiences and potential change agents.
- A gender-transformative focus to empower women and girls and strengthen their capacity to participate in and benefit from programmes to reduce stigma and discrimination.
- Programmes that address the underlying drivers of stigma and discrimination against key
 populations (beyond HIV status), in particular social attitudes towards sex work, sexual
 orientation and gender identity and drug use.

2. Focus populations

Rights-based approaches to HIV call for a particular emphasis on ensuring that the most marginalized people, those at a higher risk of infection with HIV, and those most affected by the epidemic benefit from the national response in proportion to their needs. Integrated biobehavioural surveillance and size estimates of key populations constitute important strategic information necessary for spearheading the response. Modelling-derived estimates and projections, such as modes of transmission studies, allow for evidence-based planning for the immediate and longer term.

Reducing HIV-related stigma and discrimination is critical in ensuring proportionate and equitable access to services to those most affected, in particular key populations. Epidemic and response analysis should examine how the national response adheres to the principles of equity and fairness in the determination of who benefits from programmes and the degree to which their needs are met. Analysis should consider data regarding the following: experienced stigma and discrimination, discrepancies or gaps in access to HIV services by different population groups (in particular, key populations), and the impact of activities and programmes that address and reduce the underlying causes of stigma and discrimination. Where disaggregated data on access to services, population size estimates, stigma and discrimination, including for key populations, do not exist, or where there is a lack of evidence regarding how stigma and discrimination are impacting the AIDS responses, funding should go to the collection of such data with the meaningful participation of communities.

Every national response should be based on an evidence-informed understanding of HIV-related stigma. Measurement tools are available to assess the prevalence and forms of stigma and discrimination and the reasons for this as experienced by people living with HIV, as well as the prevalence of discriminatory attitudes towards people living with HIV among the general population. The implementation of these tools can be included as part of the monitoring of the epidemic and the response in national strategic plans. Assessments should also look at the involvement of people living with HIV and key populations in the design, implementation and evaluation of HIV programmes.

There are currently several improved tools that can be used to collect data on HIV-related stigma and discrimination relating to people living with HIV. These include:

- The People Living with HIV Stigma Index, for and by people living with HIV (http://www.stigmaindex.org/), which collects data on the experiences of people living with HIV in terms of external and internal stigma.
- An improved indicator to measure discriminatory attitudes towards people living with HIV among the general population has been included in the GARPR indicators,² and two indicators on the drivers and manifestations of HIV-related stigma have been introduced

² World Health Organization, Joint United Nations Programme on HIV/AIDS, United Nations Children's Fund. Global AIDS response progress reporting 2014: Construction of core indicators for monitoring the 2011 United Nations Political Declaration on HIV and AIDS. Geneva: Joint United Nations Programme on HIV/AIDS; 2014, (http://www.unaids.org/en/ media/unaids/contentassets/documents/document/2014/GARPR_2014_guidelines_en.pdf).

in the Indicator Registry (http://www.indicatorregistry.org/?q=taxonomy/term/677), which will be collected through population-based surveys.

- A survey tool by which HIV-related stigma in health-care settings can be measured (see resources on the Stigma Action Network website at www.stigmaactionnetwork.org).
- The PLHA-Friendly Achievement Checklist, which is a self-assessment tool for hospitals and other medical institutions that provide care for people living with HIV (http://www.popcouncil.org/pdfs/horizons/pfechklst.pdf).

As yet, no tools are available to assess stigma and discrimination related to other social statuses and/or behaviours, such as gender identity, same-sex relationships, sex work and drug use.

3. Data requirements

Research has shown that the actionable causes of stigma and discrimination (and their manifestations) are remarkably similar across cultures. These causes include:

- A lack of awareness regarding stigma and its harmful consequences.
- Irrational fears and a lack of sufficient knowledge regarding HIV infection.
- Social judgements, prejudices and stereotypes against people living with HIV and other key populations.
- Structural determinants as well as a lack of frameworks to seek redress for discrimination, such as through laws and policies.

The lack of data on the prevalence of stigma and discrimination, and their actionable causes, render people living with and affected by HIV invisible. A failure to invest in collecting such data may be regarded as state-condoned discrimination of such key populations. As part of designing an effective national response to HIV, a situation analysis should be conducted with the participation of people living with and affected by HIV to assess what factors are behind stigma and discrimination and what can facilitate their reduction in different settings.

The situation analysis could seek to answer the following questions.

Structural level

Questions related to the structural level include the following:

- Are mechanisms in place to report, document and address cases of discrimination against people living with HIV or other key populations?
- Are laws in place to protect people living with HIV and other key populations from discrimination, and are those laws being enforced?
- Are laws in place and implemented that protect women and girls from discrimination, violence and gender inequality?

- Are laws in place that hinder the ability of certain groups to access HIV services (e.g. overly broad criminalization of HIV transmission, criminalization of sex work, criminalization of same-sex sexual activity, criminalization of drug use or harm reduction measures or HIV-related restrictions on entry, stay and residence)?
- Are any laws in place that limit access to services by requiring the consent of another person, such as consent from a spouse or parent?
- Are law enforcement practices discriminatory (e.g. do police harass, arbitrarily arrest or practise violence against sex workers, people who inject drugs, men who have sex with men or transgender people and, thus, interfere with access to HIV services among these populations)?
- Do people living with HIV and other key populations know their right to be free from discrimination, and do they have access to justice in the event of unfair treatment, such as through affordable and accessible legal services?

Institutional context

In relation to the institutional context, the following questions should be considered:

- Does the country have policies against HIV-related discrimination in employment, health-care settings, schools and other institutional contexts?
- Do health-care workers, police officers, judges and lawyers receive training on non-discrimination in the context of HIV?

Attitudes and behaviours

In relation to attitudes and behaviours, the following questions should be considered:

- Does the general population hold stigmatizing attitudes and exhibit stigmatizing behaviours towards people living with HIV or other key populations? What are the causes of these views?
- Do service providers in institutional settings (e.g. health workers, teachers, religious leaders and prison staff) hold stigmatizing attitudes or engage in discriminatory actions? What are the causes of these views?
- Do people living with HIV, sex workers, men who have sex with men, transgender people, people who inject drugs, prisoners, migrants, etc., experience stigma and discrimination? If so, what forms do the stigma and discrimination take and in what contexts do they occur?

4. Implementation challenges

Some of the main implementation challenges include the following.

Scale. This concerns the integration of programmes to reduce stigma and discrimination into national AIDS responses at a sufficient scale. Programmes to reduce HIV-related stigma and discrimination should be supported and expanded as needed in the national context. This means the full integration of these programmes within the national AIDS response, taking them to the scale necessary to make a difference and evaluating their impact.

Resources. Inadequate funding for programmes relating to HIV at every stage of the process also represents a challenge to implementation. Although many countries refer to programmes to reduce stigma and discrimination in their HIV strategies, these programmes are rarely taken through the full planning process—that is, from strategy to costing, budgeting, implementation, monitoring and evaluation.

Community engagement. People living with HIV and members of other key populations represent a powerful and highly underutilized resource by which to measure, design and deliver programmes to reduce stigma and discrimination. To ensure a greater impact and the sustainability of programmes, people living with HIV and key populations should be provided with resources and put at the centre of stigma-reduction efforts.

5. Main activities

Programmes designed to address critical enablers at a structural level may include the following:

- Assessment of the legal environment and law reform:
 - conducting an assessment of the legal environment to see whether all aspects of the legal environment (e.g. law, law enforcement and access to justice) are working to reduce and provide redress for HIV-related stigma and discrimination that blocks HIV prevention, treatment, care and support;
 - information and sensitization of parliamentarians for the drafting and enacting of antidiscrimination legislation that protects people living with HIV, women and girls and other key populations from discrimination;
 - removal of punitive legislation, including the criminalization of HIV transmission, sex work, drug use and harm reduction and consensual same-sex activity;
 - strengthening the legal and policy environment to ensure that laws protect women and girls from gender-based discrimination and violence and provide them with access to social, legal and health services;
 - evidence gathering, including through community-led research on stigma and discrimination experienced by people and discrimination by people living with HIV and other key populations (e.g. stigma and discriminatory attitude indicators in the general population and in health-care settings and the People Living with HIV Stigma Index).

- Training on rights for law enforcement officials to promote access to justice:
 - training of law enforcement agents, lawyers and judiciary on non-discrimination in the context of HIV;
 - joint planning and programming with ministers of interior, justice, gender/women and youth, the police and prison authorities as well as with traditional and faith-based leaders to protect people living with or affected by HIV from stigma and discrimination.
- Legal services and rights and legal literacy to promote access to justice:
 - rights and legal literacy programmes for people living with HIV, women and girls and other key populations so they may empower themselves to overcome stigma and discrimination and mobilize around their rights and relevant local laws;
 - programmes to support civil society organizations to advocate and mobilize against stigma and discrimination;
 - establishment or expansion of HIV-related legal services, alternative forms of dispute resolution and assistance with informal or traditional legal systems to provide redress against discrimination.

Programmes that address the institutional level may include the following:

- The establishment and operationalization of workplace policies against discrimination, including functioning mechanisms for redress.
- Health-care workplace programmes and training on non-discrimination and medical ethics related to HIV for health workers, social workers, uniformed services and workers in the education sector.

Programmes implemented at the community level may include the following:

- The community-led monitoring of rights violations (e.g. through initiatives such as the People Living with HIV Stigma Index).
- Participatory education programmes that address changing societal attitudes to dispel myths and fears related to people living with HIV and other key populations and HIV transmission (including comprehensive and evidenced-based sexuality education, HIV-related education, gender equality and life skills, etc.).
- Sensitizing and engaging the media and mass communications (e.g. compassionate messages from faith-based leaders, engaging celebrities and "edutainment").
- HIV-related awareness campaigns that are responsive to the needs of those most marginalized.
- Capacity strengthening of community organizations (in particular, networks of people living with HIV and other key populations) on campaigning and advocacy, and how to develop antistigma community-led programmes.
- Community-led advocacy for legal and policy reform, including developing and implementing effective systems to address complaints.

Programmes at the individual level aimed at reducing internalized and anticipated stigma may include the following:

- Counselling and psychosocial support around stigma and discrimination.
- Integrated care and support programmes for quality of life.
- Peer support and support groups (e.g. the prevention of mother-to-child transmission (PMTCT), antiretroviral therapy, addressing stigma and discrimination, adherence support, support groups).
- Legal services and redress for discrimination.

6. Key indicators

Programmes to reduce stigma and discrimination should use baseline indicators for their programmatic outcomes related to an actual reduction in stigma and discrimination (e.g. in the community and within focus populations and environments). Where possible, indicators should also demonstrate the impact of the uptake of and access to HIV testing, prevention, treatment and care.

Some current indicators that can be used to measure programme outcomes related to stigma and discrimination are described below.

- The People Living with HIV Stigma Index (http://www.stigmaindex.org/) is a programmatic tool to measure stigma and discrimination experienced by people living with HIV. The tool is implemented by and among people living with HIV in collaboration with academic institutions, governments, the United Nations and other partners.
- The MEASURE demographic and health survey core questionnaire, which is currently under review (http://www.measuredhs.com/hivdata/ind_tbl.cfm), is expected to include questions used to construct indicators on discriminatory attitudes and stigma drivers and manifestations towards people living with HIV among the general population.
- A tool for the measurement of stigma and discrimination in health-care settings has been developed (http://www.healthpolicyproject.com/index. cfm?ID=publications&get=pubID&pubID=49).
- The Global Fund Community Systems Strengthening Framework provides support for the greater involvement of people living with HIV and other key populations within national programmes. It provides relevant indicators and examples of activities.
- The National Commitments and Policy Instrument (NCPI) is an integral part of the core indicators. NCPI includes several questions that are relevant in terms of measuring the structural and institutional facilitators of stigma and discrimination and that can be used to identify changes in the legal and policy environment (which could be direct or indirect outcomes of some stigma and discrimination programmes).

Specific questions included in NCPI include the following:

- Questions that assess the existence of protective and punitive laws:
 - Does the country have non-discrimination laws or regulations that specify protections for key populations and other vulnerable groups?
 - Does the country have a general (i.e. not specific to HIV-related discrimination) law on non-discrimination?
 - Does the country have laws, regulations or policies that present obstacles to effective HIV prevention, treatment, care and support for key populations or other vulnerable populations (e.g. women and girls, young people, people who inject drugs, men who have sex with men, sex workers, transgender people, prisoners, migrants/mobile populations and people with disabilities)?
 - Does the country have a policy, law or regulation to reduce violence against women, including, for example, victims of sexual assault or women living with HIV?
- Questions that assess law enforcement:
 - Do independent national institutions exist for the promotion and protection of human rights, including human rights commissions, law reform commissions and watchdogs, and are there ombudspeople in place that consider HIV-related discrimination within their work?
 - Are there performance indicators or benchmarks for compliance with human rights standards in the context of HIV efforts?
 - In the past two years, have there been training and/or capacity-building programmes for members of the judiciary and law enforcement on HIV and human rights issues that may come up in the context of their work?
 - Overall, how would you rate the policies, laws and regulations in place to promote and protect human rights to HIV (using a 10-point scale from very poor to excellent)?
- Questions that assess access to justice:
 - Is there a mechanism to record, document and address cases of discrimination experienced by people living with HIV and/or other key or vulnerable subpopulations?
 - In the last two years, have there been training and/or capacity-building programmes to educate and raise awareness among people living with HIV and key populations concerning their rights?
- Questions related to policies and programming relevant to stigma and discrimination:
 - Is the promotion and protection of human rights explicitly mentioned in any HIV policy or strategy?
 - Does the country have a policy or strategy to ensure equal access for women and men to HIV prevention, treatment, care and support?
 - Does the country have a policy or strategy to ensure equal access for key populations and/ or other vulnerable populations to HIV prevention, treatment, care and support?
 - Does the country have a policy or law prohibiting HIV screening for general employment purposes (i.e. recruitment, assignment/relocation, appointment, promotion and termination)?
 - Are programmes in place to reduce HIV-related stigma and discrimination? If yes, what types of programmes (e.g. health-care workers, media and workplace)?

For all relevant questions and indicators in NCPI 2014 and for more information, see http://www.unaids.org/en/media/unaids/contentassets/documents/document/2014/GARPR_2014_guidelines_en.pdf.

7. Approaches to costing

The costing and budgeting of programmes to reduce stigma and discrimination are essential to their effective implementation. UNAIDS has made available the HIV-related Human Rights Costing Tool, which facilitates costing and budgeting processes for programmes aimed at reducing stigma and discrimination and increasing access to justice in the context of HIV. It supports the inclusion of such programmes in national strategic plans and helps to translate them into precise activities and indicators. This tool and its user guide are available at http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/The_HRCT_User_Guide_FINAL_2012-07-09.pdf.

8. Addressing gender, human rights and equity issues

Programmes to reduce HIV-related stigma and discrimination should help to empower people living with and affected by HIV, women and girls and other key populations. It should be implemented in ways that promote equality and non-discrimination, participation, inclusion and accountability, all of which are core elements of human rights based approaches to HIV. A special focus should be put on gender transformative programmes, since women and girls are often subject to one or more types of stigma and discrimination. Specific strategies may be required to meaningfully involve women and girls. Effective programmes and interventions identified through a comprehensive review are available in *What works for women and girls: evidence for HIV/AIDS interventions* (http://www.whatworksforwomen.org). Please also refer to the Guidance Note for gender-responsive HIV programming for women and girls.

9. Additional information

Programmes to reduce HIV-related stigma and discrimination are critical enablers necessary to increasing the efficiency, equity and roll-out of basic HIV programme activities. Although programmes to reduce HIV-related stigma may be implemented independently, it is important to integrate them into other HIV activities, such as social and behaviour change programmes, community outreach and mobilization, community and health systems strengthening, HIV testing and counselling, treatment, PMTCT, prevention among key populations and homebased care. The monitoring of stigma and discrimination among key populations will be facilitated in the near future by the inclusion of relevant questions in tools for surveys among key population groups.

Key reference materials

Websites

- The Global Commission on HIV and the Law (http://www.hivlawcommission.org)
- The People Living with HIV Stigma Index (www.stigmaindex.org)
- Stigma Action Network (www.stigmaactionnetwork.org)

Documents

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