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KEY PROGRAMMES TO REDUCE STIGMA AND DISCRIMINATION AND INCREASE ACCESS TO JUSTICE IN NATIONAL HIV RESPONSES



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KEY PROGRAMMES TO REDUCE STIGMA AND
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“Thirty years into the HIV epidemic we still have major discrimination and stigma related to HIV, as well as laws and law enforcement that drive people away from HIV services. Such situations are undermining the HIV response across the world. This will only change if we make major investments in programmes to reduce such stigma and increase access to justice for those affected by HIV.”

Michel Sidibe, UNAIDS Executive Director, August, 2011

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Why we need to eliminate stigma, discrimination and punitive approaches related to HIV

All governments have recognized that stigma, discrimination and violations of other human rights are major barriers to effective national responses to HIV. Consequently, they have committed to protect the human rights of people living with HIV, as well as the rights of women, children, and members of vulnerable and key populations in the context of HIV.¹ This not only reduces the personal suffering that can be associated with HIV, but also helps to create social and legal environments that encourage people to take up and use HIV services. Such efforts are essential to achieve universal access to HIV prevention, treatment, care and support, and to halt and reverse the epidemic – other government commitments.² For these reasons, UNAIDS has recognized “advancing human rights and gender equality” as one of three strategic pillars in the response to HIV.³

However, over thirty years into the epidemic, stigma remains high in most countries and access to justice in the context of HIV is very low. Because of stigma and discrimination, many people are afraid to get tested for HIV, to take up HIV prevention and treatment, to disclose their HIV status, and to participate in national HIV responses. They also have little chance of getting legal redress for HIV-related harms. Women continue to face discrimination and violence that make them more vulnerable to HIV, and young people often cannot access information and services for life-skills and sexual health. The criminalization of people who are at higher risk of infection, such as men who have sex with men, sex workers, transgender people and people who use drugs, drives them underground and away from HIV services. This increases their vulnerability to HIV, as well as to stigma, discrimination, marginalization and violence. Most people living with or vulnerable to HIV do not know their rights or the local laws that might protect them.

Transforming these realities for an effective and rights-based AIDS response takes leadership and courage at the highest political levels, as well as among those living with and vulnerable to HIV. Those affected by HIV have, over the years, led their communities and countries towards effective HIV prevention, fought for and won access to treatment, and demanded equality, dignity and respect. They have been, and remain, critical agents for the social and legal changes necessary for effective HIV responses.

In order to protect people living with and affected by HIV and to support effective responses to HIV, UNAIDS recommends that every national HIV response include key programmes to reduce stigma and discrimination and increase access to justice. These programmes not only help realize basic

¹ Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS (UN Resolution 65/277). June 2011, United Nations: New York. http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_UN_A-RES-65-277_en.pdf

² See Political Declaration on HIV/AIDS (UN Resolution 20/262). June 2006, United Nations: Geneva. http://data.unaids.org/pub/Report/2006/20060615_hlm_politicaldeclaration_ares60262_en.pdf and Millennium Development Goal 6 on halting and reversing the HIV epidemic

³ Joint United Nations Programme on HIV/AIDS (2010), *UNAIDS 2011–2015 Strategy, Getting to Zero*. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/JC2034_UNAIDS_Strategy_en.pdf



human rights and access to justice in the context of HIV, they are also critical enablers to the success of basic HIV prevention and treatment programmes.⁴ Such programmes should benefit both people living with HIV and those vulnerable to HIV infection, and depending on epidemic priorities, can be tailored to specific populations, e.g. people living with HIV, women, young people, men who have sex with men and transgender people, people who use drugs, migrants and refugees. Moreover, they should include a capacity-building and community mobilization component so that those affected can participate in the design and delivery of the programmes, as well as in leadership and advocacy for their HIV-related rights.

To ensure the inclusion of these programmes in national responses, UNAIDS recommends that the programmes be included in National Strategic Plans for HIV and incorporated as essential activities in operational plans. The programmes should be costed with allocated budget and be attributed indicators for monitoring progress. To facilitate this, UNAIDS has developed a set of guidance and tools. These include a manual on the programme definitions⁵ and a tool to estimate the cost of launching and developing HIV-related human right programmes (the Human Rights Costing Tool, or HRCT)⁶. This tool can be used for assessing the overall costs of these programmes at local or national level, calculating their average unit costs and estimating resources required for implementing and expanding the programmes as part of the national HIV response.

The coverage and scale of these programmes should be tailored to national and local epidemics, expanded to the point where they can make a difference, and evaluated for further learning.

⁴ For more information, please see Schwartländer B et al., *Towards an Improved Investment Approach for an Effective Response to HIV/AIDS*, The Lancet, Volume 377, Issue 9782, Pages 2031 – 2041 (11 June 2011) and UNAIDS Issues Brief (2011), *A New Investment Framework for the Global HIV Response* http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2244_InvestmentFramework_en.pdf.

⁵ To be published in 2012.

⁶ For more information, please see the UNAIDS (2012), *Human Rights Costing Tool (HRCT)* and UNAIDS Guidelines (2012), *The User Guide for the HIV-related Human Rights Costing Tool: costing programmes to reduce stigma and discrimination and increase access to justice in the context of HIV*

Key programmes for every HIV response

1. Stigma and discrimination reduction

Programmes aimed at reducing stigma and discrimination against people living with HIV or people at risk of HIV infection should address the actionable causes of stigma and discrimination and empower people living with and vulnerable to HIV. Research has shown that the actionable causes are: (a) ignorance about the harm of stigma, (b) continuing irrational fears of infection, and (c) moral judgement. Programmes to address these causes can involve a variety of approaches, including:

- Community interaction and focus group discussions involving people living with HIV and members of populations vulnerable to HIV infection;
- Use of media, including advertising campaigns, entertainment designed to educate as well as to amuse (“edutainment”), and integration of non-stigmatizing messages into TV and radio shows;
- Engagement with religious and community leaders, and celebrities;
- Inclusion of non-discrimination as part of institutional and workplace policies in employment and educational settings;
- Measurement of HIV-related stigma through the *People Living with HIV Stigma Index*⁷, including in health care settings and communities; and
- Peer mobilization and support developed for and by people living with HIV aimed at promoting health, well-being and human rights⁸.

2. HIV-related legal services

HIV-related legal services can facilitate access to justice and redress in cases of HIV-related discrimination or other legal matters. These might include: estate planning; breaches of privacy and confidentiality; illegal action by the police; discrimination in employment, education, housing or social services; and denial of property and inheritance rights. Specifically, these services may include:

- Legal information and referrals;
- Legal advice and representation;
- Alternative/community forms of dispute resolution;
- Engaging religious or traditional leaders and traditional legal systems (e.g. village courts) with a view to resolving disputes and changing harmful traditional norms; and
- Strategic litigation.

⁷ For further information, see <http://www.stigmaindex.org/>.

⁸ GNP+, UNAIDS (2009). *Positive Health, Dignity and Prevention - Technical Consultation Report* (Amsterdam). <http://gnppplus.net/en/programmes/positive-health-dignity-and-prevention>

3. Monitoring and reforming laws, regulations and policies relating to HIV

Laws, regulations and policies relating to HIV can negatively or positively impact a national HIV epidemic, as well as the lives and human rights of those living with and affected by HIV. It is thus essential to monitor and reform laws, regulations and policies so they support, and not hinder, access to HIV and health services. Examples of programmes to monitor and reform laws, regulations and policies in the context of HIV include:

- Review of laws and law enforcement practices to see whether they impact the response to HIV positively or negatively;
- Assessment of access to justice for people living with or vulnerable to HIV;
- Advocacy and lobbying for law reform;
- Engagement of Parliamentarians and Ministers of Justice, Interior, Corrections, Finance, Industry, Labour, Women's Affairs, Education, Immigration, Housing, Defence, Health and Trade, religious and traditional leaders, among others; and
- Promotion of the enactment and implementation of laws, regulations and guidelines that prohibit discrimination and support access to HIV prevention, treatment, care and support.

4. Legal Literacy (“know your rights”)

Legal literacy programmes teach those living with or affected by HIV about human rights and the national and local laws relevant to HIV. This knowledge enables them to organize around these rights and laws and to advocate for concrete needs within the context of HIV. Thus, these programmes focus on both legal and rights knowledge and on strategies regarding how to use this knowledge to improve health and justice. The programmes may also provide information on different legal or human rights fora in which one can advocate or seek redress, such as patients' rights groups, ombudsmen offices and national human rights institutions. Legal literacy programmes can form part of other HIV services (e.g. health care provision, prevention outreach, peer education, support groups, in prisons) or can be stand-alone programmes involving such activities as:

- Awareness-raising campaigns that provide information about rights and laws related to HIV through media (e.g. TV, radio, print, Internet);
- Community mobilization and education;
- Peer outreach; and
- Telephone hotlines.



5. Sensitization of law-makers and law enforcement agents

These programmes seek to inform and sensitize those who make the laws (parliamentarians) and those who enforce them (Ministers of Interior and Justice, police, prosecutors, judges, lawyers, traditional and religious leaders) about the important role of the law in the response to HIV, e.g. to protect those affected by HIV against discrimination and violence and to support access to HIV prevention, treatment, care and support. Sensitization programmes aim to help ensure that individuals living with and vulnerable to HIV can access HIV services and lead full and dignified lives, free from discrimination, violence, extortion, harassment and arbitrary arrest and detention. Such programmes may include:

- Sensitization of police regarding HIV and how it is and is not transmitted; the importance of reaching out to and accessing populations at risk; the importance of appropriately addressing domestic and sexual violence cases in the context of HIV; and the negative consequences of illegal police activity on justice and on the HIV response;
- Facilitated discussions and negotiations among HIV service providers, those who access services and police to address law enforcement practices that impede HIV prevention, treatment, care and support efforts;
- Information and sensitization sessions for Parliamentarians, personnel of Ministries of Justice and Interior, judges, prosecutors, lawyers, and traditional and religious leaders on the legal, health and human rights aspects of HIV and on relevant national laws and the implications for enforcement, investigations and court proceedings;
- Training for prison personnel regarding the prevention, health care needs and human rights of detainees living with or at risk of HIV infection; and
- HIV in the Workplace programmes for law makers and enforcers.



6. Training for health care providers on human rights and medical ethics related to HIV

Human rights and ethics training for health care providers focus on two objectives. The first is to ensure that health care providers know about their own human rights to health (HIV prevention and treatment, universal precautions, compensation for work-related infection) and to non-discrimination in the context of HIV. The second is to reduce stigmatizing attitudes in health care settings and to provide health care providers with the skills and tools necessary to ensure patients' rights to informed consent, confidentiality, treatment and non-discrimination. Human rights and ethics training should be conducted with:

- **Individual health care providers** to raise awareness of their own human rights in the context of HIV, and the negative impact that stigma, breaches of confidentiality and neglect of informed consent in health care settings have on patients' lives, as well as to address fears and misconceptions about HIV transmission and to promote understanding, compassion and professionalism;
- **Health care administrators** to ensure that health care institutions provide the information, supplies and equipment necessary to make sure health care workers have access to HIV prevention (including the universal precautions needed for prevention of occupational transmission of HIV) and treatment and are protected against discrimination; and
- **Health care regulators** to ensure enactment and implementation of policies that protect the safety and health of patients and health care workers, and prevent discrimination against people living with and vulnerable to HIV.

7. Reducing discrimination against women in the context of HIV⁹

These programmes address gender inequality and gender-based violence as both causes and consequences of HIV infection. This includes programmes that address women's and girls' inequality in sexual and reproductive decision-making; gender barriers to health services; discrimination in inheritance, property-holding, marriage, divorce and custody; sexual and other violence; lack of equal access to educational and economic opportunity; and lack of support to care-givers in HIV-affected households. Such programmes should be complemented by programmes targeting men and boys which address harmful gender norms that make women and girls, as well as men and boys, vulnerable to HIV infection. These programmes can include:

- Strengthening the legal and policy environment to ensure that laws protect women and girls from gender inequality and violence;
- Efforts to reform domestic relations and domestic violence laws and law enforcement where these fail to sufficiently protect women or create barriers to HIV prevention, treatment, care and support;
- Efforts to reform property, inheritance and custody laws to ensure equal rights for women, children and caregivers affected by HIV;
- Age-appropriate sexuality and life-skills education programmes that also seek to reduce gender inequality and gender-based violence;
- Programmes to reduce harmful gender norms and traditional practices that put women, girls, men and boys at risk of HIV infection, including capacity development of civil society groups working for women's rights and gender equality;
- Programmes to increase access to education and economic empowerment opportunities for women living with or vulnerable to HIV infection; and
- Integrated health services with a well functioning referral system, including post rape care and post exposure prophylaxis (PEP).



⁹ Some of these programmes are under further development from a gender perspective and an updated version will be provided in due course.



Human Rights Resources for HIV Responses

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