

Ensuring Equality: A Guide to Addressing and Eliminating Stigma and Discrimination in the Health Sector

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2010 – Presented the first evidence showing that CIA medical personnel engaged in human experimentation on prisoners in violation of the Nuremberg Code and other provisions

Physicians for Human Rights

2 Arrow Street, Suite 301

Cambridge, MA 02138

Tel. 617.301.4200

Fax. 617.301.4250

physiciansforhumanrights.org

Washington, DC Office:

1156 15th Street, NW, Suite 1001

Washington, DC 20005

Tel. 202.728.5335

Fax. 202.728.3053

physiciansforhumanrights.org

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This guide was written primarily by Lindsey Peugh, MPH, under the oversight and with contributions from Eric A. Friedman, JD, Senior Global Health Policy Advisor, Physicians for Human Rights (PHR).

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Introduction

Stigma and discrimination are abhorrent everywhere, resulting in human rights denied and life diminished. They are particularly pernicious in the health sector, where they obstruct individuals' right to the highest attainable standard of health¹ and hinder efforts to combat disease and social injustice worldwide. Health facilities, supposed to be places of healing, instead can impose additional pain and trauma on some of the most disadvantaged patients. The most vulnerable people around the world often face this stigma and discrimination from the very people whose job is to provide quality health services – doctors, nurses, and other health workers. This results in decreased health-seeking behavior and inadequate provision or denial of services, leaving those stigmatized even more vulnerable to ill-health and its consequences, and reinforcing the trauma of stigma.

In order to ensure the right to health for all, eliminate the barriers to care created by stigma and discrimination, and strengthen efforts to combat disease, it is imperative that countries, and where needed the development partners that contribute to their health sectors, implement interventions to reduce stigma. These efforts should be supported by laws and policies that empower marginalized communities and individuals to realize their rights to respectful and non-discriminating care, and increase healthcare workers' respect for the rights and dignity of all people.

This guide aims to assist policymakers, health workers, and civil society organizations understand health stigma and discrimination and identify the ways in which each can work to combat their expression. Eliminating health worker stigma will not eliminate all stigma and discrimination, and the experiences of marginalized populations outside of the health sector will affect how they interact – or fail to interact – with the health sector. The strategies utilized in the health sector, however, can help lead the way in serving as a model of respectful and non-discriminatory treatment of everyone.

The widespread and sometimes extreme stigma and discrimination that people with HIV/AIDS face, combined with efforts to combat AIDS and achieve universal access, has helped focus attention of policymakers and researchers on AIDS-related stigma. Accordingly, many of the examples in this guide are drawn from the HIV/AIDS context. It looks beyond HIV/AIDS as well, and aims to address the broad range of stigmas that undermine the right to health and the dignity due everyone. The guide is based largely on examples, experiences, and lessons from Africa and Asia, though has much relevance beyond these regions as well, including in the Global North.

Part I of the guide set the context for why it is necessary to address stigma and discrimination in the health sector, and other violations of patient rights. It begins with an introduction to stigma and discrimination in the health sector, including how it manifests itself and its deleterious impact on people's ability to access quality health care. The guide then looks to how discrimination in the health sector harms people in other realms of life, as well as how broader laws and social attitudes, in turn, can reduce access to quality health care of stigmatized populations. Factors both specific to and outside of the health sector are behind

¹ This guide will use “the right to health” or “the right to the highest attainable standard of health” as shorthand for the full wording of this right as contained in article 12 of the International Covenant on Economic, Social and Cultural Rights, “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” International Covenant on Economic, Social and Cultural Rights, G.A. res. 2200A (XXI), 21 U.N.GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, *entered into force* Jan. 3, 1976, at art. 12. Available at: <http://www1.umn.edu/humanrts/instreet/b2esc.htm>.

the stigma and discrimination that some health workers express, as the next section of the guide explains. As the final piece of this context-setting, part I of the guide concludes by placing issues of discrimination in the health sector in the larger context of the right to health and patient rights, and reviews some of the main patient rights.

Part II of the guide covers the necessary response – how policymakers and health workers, as well as civil society, should protect the rights of and empower patients, and respond to stigma and discrimination that interferes with people’s right to health. It begins by detailing the type of training that all health workers should receive - and actively participate in - to reduce and eliminate their expressions of stigma and discrimination. This second part of the guide next addresses structural changes, in terms of policies and health facility arrangements, needed to address this problem. The following section focuses on another set of interventions to reduce discrimination and improve respect for other patient rights, empowering patients by ensuring that they have different types of information to help them understand and exercise their rights. The guide then hones in on the responsibilities of policymakers, including by supporting and funding the aforementioned policies, with a particular focus on policymakers’ responsibility to develop patient rights charters and effective complaint mechanisms to enforce these rights. Finally, the guide briefly overviews several of the main ways to address stigma and discrimination beyond the health sector, reinforcing how this is necessary as part of a comprehensive approach to prevent stigma and discrimination from undermining people’s right to health.

A list of resources is provided at the end of this guide. And as additional resources, PHR has developed short factsheets for policymakers, health workers, and NGOs on their roles in addressing stigma and discrimination in the health sector. These, as well as an electronic version of the present guide, are available at:
<http://physiciansforhumanrights.org/library/other/stigma-reduction-guide.html>

I. The Context

1. Types of Stigma and Discrimination in the Health Sector and Their Consequences

“Far too often, the health-care system itself – including doctors, nurses, and staff responsible for the care and treatment of people living with HIV – are prime agents of HIV-related stigma and discrimination.”²

Stigma is a means of social control of a dominant group over those perceived to be socially inferior. Stigma devalues individuals and groups based on characteristics such as sex, sexual orientation and gender identity, skin color, caste level, religion, disease, or disability. Fear of those who are perceived to threaten social values or community wellness is at the core of stigma and often stems from ignorance of marginalized populations or health conditions. This has historically been the case with conditions such as leprosy, epilepsy, HIV/AIDS, physical disabilities, and mental illnesses. It is also common with socially taboo or illegal activity like injection drug use and commercial sex work. People fear contracting disfiguring, debilitating

² UNAIDS, *2008 Report on the global AIDS epidemic* (2008), at 77. Available at: http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp.

illnesses, often associate them with socially unacceptable behavior, and place blame and moral judgment on individuals with these characteristics.

Characteristics upon which people may be subject to stigma and discrimination include:

- Physical characteristics, such as sex, skin color, or physical disability.
- Identity or social status, such as gender identity, ethnicity, or class.
- Disease status, such as HIV/AIDS, leprosy, or mental illness.
- Engaging in or being perceived to engage in criminalized or otherwise disapproved behavior, such as drug use, sex work, or same-sex relationships.
- Seeking criminalized or otherwise disapproved health services.

Stigma – and the resulting mistreatment – is often particularly severe against people who have several characteristics subject to stigma (such as a poor, indigenous woman, or an HIV-positive drug user).

Discrimination occurs when people or institutions act upon stigma, and entails unjust action or inaction toward individuals. It arbitrarily distinguishes, restricts, and excludes individuals, and leads to the denial of rights and services.³ Discrimination in itself is a breach of human rights. And the ramifications of discrimination can further deny individuals' human rights. Stigma and discrimination in health facilities have serious and far-reaching implications on health-seeking behavior, and on people's experiences when they do seek health care. This impact contributes to marginalized individuals' greater vulnerability to ill health and decreased ability to obtain quality health services. This effect goes even beyond the stigmatized individuals and can undermine key national public health initiatives. For example, by obstructing efforts to combat illnesses such as HIV among particularly high-risk populations, stigma and discrimination can accelerate the spread of the disease into the general population. The double impact - on both the marginalized populations and general populations - hinders national and global efforts to tackle disease and inequalities.

“Stigma, silence, discrimination and denial, as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations.”

Declaration of Commitment on HIV/AIDS (June 2001), at para. 13. Available at: <http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>

Stigma and discrimination reinforce and legitimize each other, operate at multiple levels, and can be expressed in many forms.

- **Denial of care**

³ UNAIDS, *HIV – Related Stigma, Discrimination and Human Rights Violations* (2005). Available at: http://data.unaids.org/publications/irc-pub06/JC999-HumRightsViol_en.pdf.

Stigmatized individuals are sometimes denied care entirely. This can happen directly, when health workers refuse to care for certain people. A study in Nigeria in the 1990s found that 64% of doctors believed they had the right to choose whether or not to treat an HIV-positive individual and 50% believed that denial of care was not unethical.⁴ Another survey in Nigeria, conducted in 2002, reported that 9% of health workers interviewed had refused to provide care to an HIV-positive person.⁵ An HIV-positive woman in Chile reports how oncologists kept sending her to different doctors to receive surgery, but none would perform the surgery because, as one oncologist conceded, she had HIV/AIDS.⁶ Other form that denial of care can take is when health staff refuse to schedule (or cancel) appointments for stigmatized populations⁷ or when one hospital transfers stigmatized individuals to another facility.⁸

Stigma and discrimination can also work to indirectly deny people care by leading to poor quality care or abuse that cause people to avoid seeking needed health services. Related violations of patients' rights, such as a breach of confidentiality, can also combine with the stigma and discrimination marginalized populations face to indirectly lead to people being denied care. For example, some HIV-positive women in Kenya choose to deliver at home rather than in a health facility because they do not trust in the confidentiality at health facilities.⁹

In a study of healthcare stigma set in Beijing, interviews with people living with HIV/AIDS revealed that denial of care based on HIV status was common and often HIV-positive patients were given false reasons for the refusal of treatment.

Yi Yang, Kong-Lai Zhang, Y. Chan, Daniel Reidpath, "Institutional and structural forms of HIV-related discrimination in healthcare: A study set in Beijing." *AIDS Care* (July 2005) 17(Supp 2): 129-140

- **Substandard care and abuse**

Many stigmatized individuals experience substandard care, and even abuse. For example, in facilities where patients are required to pay user fees, health workers have been reported to stigmatize patients who appear poor and unable to pay for fees leading to mistreatment and a lower standard of care provided.¹⁰ Substandard care can take various forms, such as the physical, verbal, and structural expressions described below.

- **Physical expressions**

⁴ I.O. Olubuyide. "Doctors at Risk of hepatitis B and HIV infection from patients in Nigeria." *Journal of the Royal Society for the Promotion of Health* (June 1996) 116(3):157-160.

⁵ Physicians for Human Rights, *Nigeria: access to health care for people living with HIV/AIDS* (2006), at 24. Available at: https://s3.amazonaws.com/PHR_Reports/nigeria-access-to-health-care.pdf

⁶ Center for Reproductive Rights, *Violations of the Rights of HIV-Positive Women in Chilean Health Facilities* (working title) (July 2010 draft), at 21.

⁷ *Id.* at 13, 30.

⁸ UNAIDS, *HIV and AIDS-related stigmatization, discrimination, and denial: forms, contexts and determinants: Research Studies from Uganda and India* (2000), at 23-24. Available at: http://data.unaids.org/Publications/IRC-pub01/JC316-Uganda-India_en.pdf.

⁹ Janet M. Turan, S. Miller, E.A. Bukusi, J. Sande, & C.R. Cohen, "HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services." *AIDS Care* (Sept. 2008) 20(8): 938-945, at 940.

¹⁰ Personal communication with Elisa Slattery, Regional Manager and Legal Adviser, Africa Program, Center for Reproductive Rights, Aug. 3, 2009.

Physical discrimination can occur in a health facility when health workers use special markings to identify those with a stigmatized condition, use excessive precautions, or avoid contact with patients. Hospital workers in Mumbai, India, for instance, reported keeping tubs of disinfectant under the beds of HIV-positive patients in order to soak sheets and instruments before regular washing. Others reported writing “HIV” on patient charts, which were visible to all, to designate an HIV-positive status.¹¹ HIV-positive women in Chile have reported similar practices by health workers there.¹² Physical isolation is another way in which individuals can be stigmatized. One report described practices in India of isolating HIV/AIDS patients into wards separate from other patients.¹³ An earlier report, also on India, found that several hospitals had beds designated for patients with HIV to enable hospital staff to easily identify them. These beds that were not in the middle of other patients for fear that they would infect the other patients with HIV.¹⁴

- **Verbal expressions**

Health workers can stigmatize individuals and express moral judgment through derogatory labels or other harsh, discriminatory language. Interviews with men who have sex with men (MSM) in South Africa showed that they were frequently subjected to verbal harassment from health workers. The health workers often used offensive terms to refer to MSM patients and expressed moral judgments regarding their sexual behavior.¹⁵ In another example, women with fistula have reported being treated in demeaning ways by professionals who refer to the women as “the wretched of the earth” or “women who cannot even be successful prostitutes.”¹⁶

- **Structural expressions**

Structural stigma and discrimination occurs when health facilities are not equipped to care for or treat certain individuals. This is often due to social beliefs and national or institutional policies. For example, a report from the Open Society Institute on sexual health and human rights in Thailand noted that because of negative attitudes within the Thai government and health sector toward transgender individuals, many clinics for sexually transmitted infections are ill-equipped to provide care for transgenders.¹⁷

- **Stigmatizing policies**

¹¹ UNAIDS, *HIV and AIDS-related stigmatization, discrimination, and denial: forms, contexts and determinants: Research Studies from Uganda and India* (2000). Available at: http://data.unaids.org/Publications/IRC-pub01/JC316-Uganda-India_en.pdf.

¹² Center for Reproductive Rights, *Violations of the Rights of HIV-Positive Women in Chilean Health Facilities* (working title) (July 2010 draft), at 19.

¹³ Nita Mawar, Seema Sahay, Apoorva Pandit & Uma Mahajan, “The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs.” *Indian Journal of Medical Research*, (Dec. 2005) 122:471-484, at 476.

Available at: <http://www.icmr.nic.in/ijmr/2005/december/1201.pdf>.

¹⁴ UNAIDS, *HIV and AIDS-related stigmatization, discrimination, and denial: forms, contexts and determinants: Research Studies from Uganda and India* (2000), at 24. Available at: http://data.unaids.org/Publications/IRC-pub01/JC316-Uganda-India_en.pdf.

¹⁵ Tim Lane, T. Mogale, H. Struthers, James McIntyre & S.M. Kegeles, “‘They see you as a different thing’: the experiences of men who have sex with men with healthcare workers in South African township communities.” *Sexually Transmitted Infections* (2008) 84: 430-433.

Available at: <http://sti.bmj.com/content/84/6/430.full.pdf>.

¹⁶ Maggie Bangser, “Obstetric fistula and stigma.” *Lancet* (Feb. 11, 2006) 367: 535-36.

¹⁷ Sexual Health and Rights Program, Open Society Institute, *Sex Workers, Transgender People and Men Who Have Sex with Men: Thailand* (2006), at 31. Available at: <http://www.hivpolicy.org/Library/HPP001169.pdf>.

The presence or absence of institutional policies and procedures can contribute to the stigmatization and discrimination of individuals. For instance, rights are compromised when patients are detained in health facilities for their inability to pay for services, a practice that has primarily reflected and reinforced broader societal discrimination against women. In 2006, patients in Burundian public hospitals could be detained for weeks or months, guarded by hospital security and staff, and often kept in separate rooms from other patients. Detained patients were frequently left without medical treatment, without a bed and with little food, even as daily hospital charges continued to accrue.¹⁸ In Sierra Leone, women are often asked to pay for services before the services are provided. The fees charged can be based on the health workers judgment of the woman's ability to pay.¹⁹

These institutional elements can disproportionately affect certain groups, placing them at an even greater risk for inadequate care. Patients requiring surgery or long-term care for chronic illnesses including HIV/AIDS are left more susceptible to being detained due to the high cost of such treatments. While both men and women can be victims of detention, women are particularly vulnerable with significant numbers being detained due to an inability to pay for complicated birth procedures like caesarian sections.²⁰ HIV-positive women may face the same fate because of high costs encountered during delivery services such as having a caesarian section to reduce the risk of vertical HIV transmission. Detention can also be used by an abusive spouse to exert control over his wife by not paying her maternity bills, abandoning her and even their baby.

As described more below, national laws and policies can also contribute to discrimination. For example, laws that criminalize certain behavior, such as same-sex relationships, injecting drug use, or sex work can help fuel discrimination against people who engage in or who health workers believe are engaged in these behaviors.

¹⁸ Human Rights Watch. *A High Price to Pay: Detention of Poor Patients in Burundian Hospitals* (Sept. 2006). Available at: <http://www.unhcr.org/refworld/docid/4517cb544.html>. In May 2006 the President of Burundi declared "free birth and delivery services and medical care for children under five years," which prohibits the detention of patients. However, there were mixed results because plans to account for increased health-seeking behavior and added stress on health workers was not taken into account. UNICEF, *Mixed blessings: Burundi's free birth delivery and medical care for under-five children* (2007). Available at: http://www.unicef.org/har07/index_37428.htm.

¹⁹ Gouri Sadhwani, *The women I met in Sierra Leone are lucky to be alive*, Sept. 22, 2009 <http://blog.amnestyusa.org/escr/the-women-i-met-in-sierra-leone-are-lucky-to-be-alive/>.

²⁰ Personal communication with Elisa Slattery, Regional Manager and Legal Adviser, Africa Program, Center for Reproductive Rights, Aug. 3, 2009.

“Widowed and HIV-positive, Beatrice Acheing had no money to have her baby delivered in a hospital. But she admitted herself anyway to reduce the risk of transmitting the virus during childbirth. To her relief, the boy was born HIV-negative. But their ordeal had just begun. Hours after labor, both mother and baby were shunted into a locked, guarded room with other indigent patients. They were given one meal, sometimes two, a day, but no clothes or diapers for the infants. Nurses visited sporadically, mostly harassing them to pay their bills.”

Edmund Sanders, “In Kenya, patients held hostage to medical bills.” *Los Angeles Times*, June 27, 2009. Available at: <http://articles.latimes.com/2009/jun/28/world/fg-kenya-healthcare28>

“I had to come to hospital because I needed a caesarean delivery. When I got the bill, the doctor said to me, ‘Since you have not paid, we will keep you here.’ Life here is difficult. I don’t have permission to leave with my baby. We are often hungry here. I cannot stand this situation any longer.”

- Eighteen-year-old woman held with her baby at Louis Rwagasore Clinic, Bujumbura

Human Rights Watch, *A High Price to Pay: Detention of Poor Patients in Burundian Hospitals* (Sept. 2006). Available at: <http://www.unhcr.org/refworld/docid/4517cb544.html>

- **Violating patients’ rights**

Stigma and discrimination violate the rights that people have as patients, including to non-judgmental, non-discriminatory, and respectful treatment. But that is not all. Such attitudes, policies, and practices can lead to further violations of people’s right to health, and their rights as patients, which are further detailed below. In the study of MSM in South Africa, men reported that health workers often gossiped about their conditions, jeopardizing their right to privacy and increasing the likelihood of experiencing stigma and discrimination in other realms of life.²¹ In a 2006 study, maternity workers at a hospital in Kenya reported that even if a woman expressed that she did not want her HIV-positive status revealed to her husband, sometimes maternity workers would tell him anyway.²² The consequences of having one’s HIV positive status revealed can be devastating. It creates the probability that women will be physically and verbally abused by their spouses, abandoned by their families, and ostracized by their communities.

In some contexts, violations of patients’ rights are quite widespread. Nearly two-thirds of respondents in a 2004 study of HIV-positive women in Chile reported that health workers only sometimes – or never – respected their rights.

Study cited in: Center for Reproductive Rights, *Violations of the Rights of HIV-Positive Women in Chilean Health Facilities* (working title) (July 2010 draft), at 20

- **Anticipation of stigma and discrimination**

²¹ Tim Lane, T. Mogale, H. Struthers, James McIntyre, S.M. Kegeles, “They see you as a different thing’: the experiences of men who have sex with men with healthcare workers in South African township communities.” *Sexually Transmitted Infections* (2008) 84: 430-433. Available at: <http://sti.bmj.com/content/84/6/430.full.pdf>.

²² Janet M. Turan, S. Miller, E.A. Bukusi, J. Sande, & C.R. Cohen, “HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services.” *AIDS Care* (Sept. 2008) 20(8): 938-945, at 942. The husband might find out in other ways, such as by coming to the maternity unit and seeing that the baby is receiving ARVs. *Id.*

Individuals may anticipate that they will experience stigma and discrimination in health facilities. This is because they understand the social and cultural beliefs of their community or have experienced mistreatment by health workers in the past. Anticipation of stigma can lead to fear and mistrust of health workers, deterring individuals from seeking health services. This is especially true concerning for conditions that require long-term treatment or care such as epilepsy, tuberculosis, or HIV/AIDS. For instance, a study of leprosy counseling groups in Nepal from 1994 to 1998 showed that perceived stigma prevented individuals with leprosy from seeking care and resulted in lower compliance with treatments.²³ HIV-positive women in Chile reported that they avoided necessary health services, or delayed seeking services until their condition had deteriorated, because they had been discriminated against in the past and so feared mistreatment in the future.²⁴

Women in maternity care units in Kenya have expressed fear of being tested for HIV without consent, having the results disclosed to family members without permission, and being stigmatized if the result was HIV-positive. The women's fears led them to decrease their use of facility-based labor and delivery services.²⁵

These concerns have also led some female patients who did seek care to avoid being tested for HIV or, if they knew that they were HIV-positive, from disclosing their status. However, not disclosing one's status may not protect against discrimination. One study found that health workers treated women with unknown HIV status worse than they treated women with known HIV status - whether positive or negative. Health workers were anxious around women with unknown HIV status and assumed these women were just hiding a positive status. Most women with an unknown status received no counseling on infant feeding, family planning, or HIV prevention which was not the case with HIV-positive women. Failure to provide all patients accurate information in these instances hinders effort to prevent vertical HIV transmission, to increase child nutrition, and to increase women's access to family planning options.²⁶

A study of maternity facilities in Kenya from 2007 found that health workers often gave women with HIV inadequate information regarding family planning and alternative infant feeding methods, and even rebuked women if they became pregnant – even though the health workers had denied them access to contraception. This affected the women's ability to make informed decisions about their health, reduced their ability to prevent HIV transmission to their sexual partners and children, and hampered their ability to negotiate safe sex practices.

Jessica Ogden & Laura Nyblade (International Center for Research on Women), *Common at its core: HIV-related stigma across contexts* (2005). Available at: <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>

²³ M. Floyd-Richard & S. Gurung, "Stigma reduction through group counselling of persons affected by leprosy—A pilot study." *Leprosy Review* (2000) 71: 499-504.

²⁴ Center for Reproductive Rights, *Violations of the Rights of HIV-Positive Women in Chilean Health Facilities* (working title) (July 2010 draft), at 13, 33.

²⁵ Janet M. Turan, S. Miller, E.A. Bukusi, J. Sande, & C.R. Cohen, "HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services." *AIDS Care* (Sept. 2008) 20(8): 938-945.

²⁶ *Id.* at 943-944.

- **Self-stigma**

Individuals living with stigmatized conditions often experience “self-stigma” which manifests as feelings of worthlessness, shame, and low self-esteem. It can occur when individuals blame themselves for their condition.²⁷ Feelings of negative self-worth were reported by 78% of people living with HIV/AIDS surveyed in a 2006 study in South Central China. HIV-positive injection drug users (IDUs) reported even higher levels of negative self worth, leading to social isolation.²⁸ Such isolation can reduce opportunities for HIV prevention, care, and treatment. In a study of individuals with schizophrenia, self-stigma was associated with a lower quality of life and increased social withdrawal leading to poor mental health, decreased economic opportunities and decreased health-seeking behavior.²⁹ By reducing people’s sense of worth, negative remarks from health workers can reduce the capacity of people, such as those living with HIV/AIDS, to care for themselves and take control of their own health.³⁰

Summary: The harms to health of stigma and discrimination

The twin ills of stigma and discrimination express themselves in the health sector in various ways, including by leading health workers to deny or delay providing care or by verbally abusing patients. This discrimination often leads people to avoid seeking necessary health services and may make quality care unavailable when they to seek care. This harms not only their own health, but also weakens prevention efforts by denying people the information, medications, or commodities that could provide them the means to prevent the spread of disease. Cumulatively, these impacts on individuals have detrimental effects on efforts to achieve major international health targets, such as reducing maternal mortality and achieving universal access to treatment for HIV/AIDS and reproductive health services.

2. Effects and Causes Outside the Health Sector

- **Social and economic**

“I am no more considered a person in my family. My father-in-law blames me for his son becoming HIV positive. I do take total responsibility for my son being positive....My father-in-law came and took his son and grandson away from me and left me in a house where I have no source of support...I have nowhere to go.”³¹

- Female with HIV/AIDS

²⁷ Jessica Ogden & Laura Nyblade (International Center for Research on Women), *Common at its core: HIV-related stigma across contexts* (2005). Available at: <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>.

²⁸ Xianhong Li, Honghong Wang, Ann Williams & Guoping He, “Stigma Reported by People Living with HIV in South Central China.” *Journal of the Association of Nurses in AIDS Care* (Jan./Feb. 2009) 20(1):22-30. Available at: <http://www.kit.nl/smartsite.shtml?ch=FAb&id=29094>.

²⁹ Graham Thornicroft, Elaine Brohan, Diana Rose, Norman Sartorius & Morven Leese, “Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey.” *Lancet* (Jan. 31, 2009) 373: 408-415.

³⁰ Center for Reproductive Rights, *Violations of the Rights of HIV-Positive Women in Chilean Health Facilities* (working title) (July 2010 draft), at 33.

³¹ Family Health International. *Women and HIV/AIDS: Experiences and Consequences of Stigma and Discrimination - Nepal* (c. 2004), at 4. Available at: <http://www.fhi.org/NR/rdonlyres/ed3e6f2uuesonsukflop7quewh7meoh37gqhybvwrzz25dn675a4pu56nf5enzo7mb73xekndnme/stigmadiscrimina0tionwomennepal2004noenhv.pdf>

“All arrangement for my marriage had been done in the village where I used to work. Then...the whole village came to know that I had leprosy. So, the marriage could not take place.”³²

- Male with leprosy in Nepal

Stigma and discrimination in the health sector have serious implications for the societal costs of disease, as well as harming people’s lives and rights outside of the health sector. For example, stigma towards elderly with mental illness leads to delayed diagnosis of mental disorders, inadequate treatment, poor quality of life, unnecessary institutionalization or warehousing.³³ It may also lead to unemployment or abuse of the elderly. Health workers who provide care for the elderly sometimes have a low professional status, leading to high attrition rates among these health workers. Considering the increasing ageing of populations around the world, these burdens can be expected to increase if stigma and mental illness are not addressed in policies, health worker education, and social campaigns.

The effects of stigma and discrimination can amplify existing social inequalities. For example, a breach of confidentiality in the health sector that reveals an individual’s HIV positive status can lead to devastating repercussions ranging from loss of livelihoods and being abandoned by family or a spouse to being physically assaulted or threatened with violence.³⁴ It can also lead to being kicked out of one’s home or suffering shame and blame from family members. These consequences are especially likely for women. Unmarried HIV-positive women may be considered unwanted, affecting their potential to have a family.³⁵ The same potential impact on marriage can exist for men with stigmatized conditions, as reported on a study of individuals with leprosy in Nepal.³⁶

- **Discriminatory laws and policies**

“...police [in Jamaica] continue to detain outreach workers and the fear of violence from the wider society hampers condom distribution and HIV/AIDS education programmes.”³⁷

Laws and policies that are discriminatory or fail to protect people from discrimination often harm health.³⁸ For example, the criminalization of drug use and police actions to harass or arrest injecting or other drug users when they are seeking health services deters drug users from seeking health services. Likewise, the criminalization in many countries of

³² Leony Try, “Gendered experiences: marriage and the stigma of leprosy.” *Asia Pacific Disability Rehabilitation Journal* (2006) 17(2): 55-72, at 63. Available at:

<http://www.aifo.it/english/resources/online/apdrj/apdrj206/gender-lep.pdf>.

³³ World Health Organization (WHO), *Reducing stigma and discrimination against older people with mental disorders* (2002). Available at: http://www.who.int/mental_health/media/en/499.pdf.

³⁴ International Center for Research on Women, *HIV/AIDS Stigma: Finding solutions to strengthen HIV/AIDS Programs* (2006). Available at: <http://www.icrw.org/files/publications/HIV-AIDS-Stigma-Finding-Solutions-to-Strengthen-HIV-AIDS-Programs.pdf>.

³⁵ Jessica Ogden & Laura Nyblade (International Center for Research on Women), *Common at its core: HIV-related stigma across contexts* (2005). Available at: <http://www.icrw.org/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>.

³⁶ Leony Try, “Gendered experiences: marriage and the stigma of leprosy.” *Asia Pacific Disability Rehabilitation Journal* (2006) 17(2): 55-72. Available at: <http://www.aifo.it/english/resources/online/apdrj/apdrj206/gender-lep.pdf>.

³⁷ Zadié Neufville, “HEALTH-JAMAICA: Fear Among Gay Men Said to Fuel HIV/AIDS Cases.” *Inter Press Service*, March 5, 2002. Available at: <http://www.aegis.com/news/ips/2002/Ip020302.html>.

³⁸ Scott Burris, “Stigma and the law.” *Lancet* (Feb. 11, 2006) 367: 529-531.

homosexuality or homosexual behavior drives sexual minorities underground. This makes it difficult for health services to reach these groups.

In Mauritania and Sudan, for instance, men who have sex with men can be sentenced to death. In many other countries, men who have sex with men can be jailed. In many countries, such as Thailand, with stringent drug use policies, injection drug users are targeted by law enforcement, who position themselves outside of clinics and needle exchange facilities.³⁹ Faced with risk of arrest, many injecting and other drug users will avoid these facilities, undermining efforts to provide them disease prevention and other health services.

When national policies do not protect the right to health for all, vulnerable individuals often avoid health and risk-reduction services, putting these individuals at an even greater danger of contracting disease or obtaining substandard care. This will be the case even if the health services themselves are free from stigma and discrimination against these groups - though even that is often not the case. And despite professional codes that pledge health workers to protect the confidentiality of patient information and provide services to those in need, many might feel obligated to disclose a patient's identification with criminalized behaviors to law enforcement, or might refuse to treat an individual for fear that they would then themselves be breaking the law. Thus, inequalities and stigma that exist beyond the health sphere need to be addressed directly not only for their own sake, but also to secure people's right to health.

- **Social and cultural attitudes and practices**

Attitudes rooted in inequality and insufficiently countered by the state can have a similar impact. If women need to seek permission from their husbands to seek health services, their access to these services will be diminished however respectfully they may be treated once they reach health. The same devaluing of women and their rights that might require a woman to seek her husband's permission before visiting a health center might also contribute to health workers' own failure to respect women and their rights. Or it might lead to health workers to refuse to provide care to women seeking health services if they have not received spousal consent - and to a lack of government action to address this violation of women's rights.

³⁹ Kaiser Family Foundation. "Thailand's New Campaign Against Illegal Drugs Will Undermine HIV/AIDS Efforts, Advocates Say." *Kaiser Daily HIV/AIDS Report*, April 10, 2008. Available at: http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=1&DR_ID=51447.

Summary: Effects and causes of health sector discrimination beyond the health sector

Stigma, discrimination, and mistreatment within the health sector often have harmful consequences that extend into other realms of people's lives. For example, a health worker's authorized disclosure of a woman's HIV positive status may subject her to violence at the hands of her partner, or to her being kicked out of her home. Conversely, national policies and practices that discriminate against or criminalize the behavior of populations such as homosexuals and drug users may drive members of these populations underground. As they try to avoid contact with law enforcement, they also become difficult to reach with health services. Laws that require health workers to violate patients' rights to confidentiality and report to law enforcement patients engaged in stigmatized, criminalized behavior pose an added burden to effective health care.

3. Why do Health Workers Express Stigma and Discrimination?

Incorrect and insufficient information, inadequate resources to prevent and treat illness, fear of contracting disease, a misunderstanding of patients' rights, social and moral beliefs, and stress and heavy workloads all have been identified as underlying causes of health workers' expression of stigma and discrimination.

- **Lack of information**

Many health workers identify lack of accurate information about the prevention and spread of disease - itself a significant impediment to their ability to provide quality health services - as a major reason for their unwillingness to work with patients with certain illnesses. A 2005 review of epilepsy in South Africa demonstrated that insufficient training left many physicians and mid-level providers unable to properly treat and diagnose epilepsy - and to often attribute the condition to supernatural causes. This contributed to their unwillingness to provide care for people with epilepsy.⁴⁰

Health workers often have misconceptions about marginalized populations. A study of people with disabilities in Swaziland published in 2004 found that health workers often considered people with disabilities to be asexual, and therefore did not provide information on sexual health. Not only is this inaccurate, but in fact women with disabilities more commonly reported being sexually exploited, increasing their risk for HIV infection. Health workers' lack of knowledge and understanding is one reason, according to the results, that individuals with disabilities were less informed about HIV/AIDS and more apprehensive about seeking health care. This study draws attention for the need to provide accurate information to health workers, particularly about people with disabilities.⁴¹ Similarly, health workers might believe the myth that homosexuality does not exist in their country or that it has been exported from

⁴⁰ Roy Baskind & Gretchen Birbeck, "Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease." *Epilepsy & Behavior* (2005) 7: 68-73. Available at:

<http://www.epilepsyfoundation.org/epilepsyusa/yebeh/upload/epilepsyinafrica.pdf>.

⁴¹ Aisha Yousafzai, Phindile Dlamini, Nora Groce & Sheila Wirz, "Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland." *International Journal of Rehabilitation Research* (2004) 27(3): 247-251. Available at:

http://globalsurvey.med.yale.edu/knowledge_personal_risk_experiences_swaziland.pdf. AIDS-Free World reports that "[a]necdotal evidence suggests a risk of HIV infection twice as high as that faced by the non-disabled population." AIDS-Free World press release, *People with Disabilities Are at High Risk of HIV but Absent from AIDS Statistics - 650 million individuals worldwide are living with a disability*, Aug. 4, 2008. Available at: <http://www.aidsfreeworld.org/images/stories/aidsconference/final%20press%20release%20disabilities.doc>.

the West. Or they might have little understanding of the difficult life circumstances of many people who use drugs or of the power of addiction.

The importance of accurate health worker knowledge was also emphasized in a 2002 WHO report on mental disorders among the elderly. The report pointed to the need to educate health workers on the specific needs and vulnerabilities of old people and their susceptibility to mental illness so that stigma toward these individuals is decreased and diagnoses and care are not delayed.⁴²

Health workers might also be unaware of their professional and legal obligations to respect patient rights. And they might not know what these rights are, or they could misunderstand their obligations with respect to these rights. For example, health workers might believe that if a woman tests HIV-positive, the health worker should always inform her husband of her status. In fact, this violates her right to confidentiality; the health worker may only so inform the woman's spouse if the woman has given the health worker permission to do so.

- **Inadequate resources**

Health workers must be provided with working conditions that support proper care and respect for patient rights. Due to factors such as financial constraints, inadequate prioritization of safe working conditions, understaffing, and deficient or failure to implement infection control policies, many health facilities do not provide safe working environments for health workers or their patients. Health workers are often not provided with the necessary tools such as gloves, syringe disposal bins, or post-exposure prophylaxis (PEP) to prevent the transmission of disease and are often not properly trained in techniques to prevent occupational transmission.⁴³

Without accurate knowledge and supplies for proper disease prevention, treatment, and care, health workers may fear contracting the disease from their patients, and be less willing to treat patients with stigmatized health conditions. Or they may do so only after taking measures (such as wearing protective gear only when working with patients who are HIV-positive) that contributes to further stigmatization. This fear among health workers of becoming infected thus creates a barrier to care for these patients and reduces the quality of care that they do receive.

⁴² WHO, *Reducing stigma and discrimination against older people with mental disorders* (2002). Available at: http://www.who.int/mental_health/media/en/499.pdf.

⁴³ Marjolein Dieleman, Godfrey Biemba, Simon Mphuka, Karen Sichinga-Sichali, Dagmar Sissolak, Anke van der Kwaak & Gert-Jan van der Wilt, "We are also dying like any other people, we are also people': perceptions of the impact of HIV/AIDS on health workers in two districts in Zambia." *Health Policy & Planning* (2007) 22: 139-148; Janet M. Turan, S. Miller, E.A. Bukusi, J. Sande, & C.R. Cohen, "HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services." *AIDS Care* (Sept. 2008) 20(8): 938-945.

Available at: <http://heapol.oxfordjournals.org/cgi/reprint/22/3/139>.

A PHR report on access of people with HIV/AIDS to health services in Nigeria, based on surveys conducted in 2002 and 2003, found that:

- *Lack of information:* 78% of respondents believed that at least under some circumstances, it was appropriate to test a patient for HIV without her knowledge or permission. More than half of health professionals reported that they obtained informed consent for HIV tests that they ordered half the time or less.
- *Lack of resources:* Health workers reported that Nigerian health facilities did not always provide adequate protective supplies. People with HIV/AIDS believed that fear of being infected and concern about contamination of instruments, material, or the health facility were top concerns of doctors and nurses about treating people with HIV/AIDS.

Physicians for Human Rights, *Nigeria: access to health care for people living with HIV/AIDS* (2006), at 21, 22, 38. Available at: https://s3.amazonaws.com/PHR_Reports/nigeria-access-to-health-care.pdf

- **Stressful work environments**

Stressful work environments and heavy workloads for health workers can lead to health worker burnout with a loss of productivity and the provision of inadequate, substandard care for patients.⁴⁴ This is especially the case in communities where HIV is prevalent and where the availability of treatment is limited.

Increasing patient numbers along with deficient infrastructure, insufficient investments in the health workforce, migration, inadequate health workforce policies, and the direct effect of the HIV/AIDS epidemic on health workers have contributed to health worker shortages and heavy workloads. It may seem that health workers should easily be able to access health services; however, many health workers have reported being deterred from seeking treatment and care for HIV/AIDS. They are fearful of the stigmatizing actions and attitudes of health workers as well as other patients.⁴⁵ They may worry that disclosing their own status will lead to their own stigmatization, such as by being labeled as promiscuous.⁴⁶

Because of these fears, health workers often do not take care of themselves adequately, one reason the HIV/AIDS epidemic can take such a toll on the health workforce. A 2007 report on health workforce in Southern Africa stated that the number one cause of health worker attrition in Malawi, Lesotho, and Mozambique is death, primarily from HIV/AIDS.⁴⁷ This further weakens already inadequate health workforces.

These situations also cause many health workers to suffer from high stress. This affects their provision of care and can lead to discriminatory behavior towards patients. In a study of women's rights violations in Kenyan health facilities, health workers noted that poor working

⁴⁴ William Holzemer, Leana Uys, Maureen Chirwa, Mirnie Greeff, Lucia Makoae, Tecla Kohi, Priscilla Dlamini, Anita Stewart, Joseph Mullan, René Phetlh, Dean Wantland & Kevin Durrheim, "Validation of the HIV/AIDS Stigma Instrument - PLWHA (HASI-P)." *AIDS Care* (2007) 19(8): 1002-1012.

⁴⁵ WHO, *Taking stock: Health worker shortages and the response to AIDS* (2006, reprinted 2007), at 4. Available at: http://www.who.int/healthsystems/task_shifting/TTR_response.pdf.

⁴⁶ Janet M. Turan, S. Miller, E.A. Bukusi, J. Sande, & C.R. Cohen, "HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services." *AIDS Care* (Sept. 2008) 20(8): 938-945, at 943.

⁴⁷ Médecins Sans Frontières, *Confronting the health care worker crisis to expand access to HIV/AIDS treatment: MSF experience in southern Africa* (2007), at 17. Available at: http://doctorswithoutborders.org/publications/reports/2007/healthcare_worker_report_05-2007.pdf.

conditions demoralized staff. The working conditions affected health workers' ability to provide adequate care, while also threatening the health of women and children in the facilities. Women patients suffered physical or verbal abuse and were often attended to by untrained staff and medical students or were not attended to at all. This caused many women to suffer unnecessary medical trauma.⁴⁸

- **Social and cultural attitudes and beliefs**

Health workers are members of the communities and societies in which they live. They will often therefore share the attitudes that are common within the dominant belief systems. For example, where homophobia is prevalent, health workers may well hold negative attitudes towards and be more likely to discriminate against sexual minorities. Where women have a low status and such practices as husbands abusing their wives are widely viewed as acceptable even by women themselves, health workers may be more likely to mistreat women themselves.

- **Discriminatory laws**

Laws criminalizing certain behavior, such as drug use, sex work, or same sex relationships, may lead health workers to violate the rights of their patients because they may believe that the law compels them to do so. For example, despite people's right to confidentiality, health workers who learn during the course of care that a patient is a drug user may feel that they must report the person to the police to help uphold the law and to avoid any risk that they themselves might be prosecuted or harassed by the police for having failed to do so.

The impact of these laws, as well as the connections between health workers' attitudes and beliefs that are common in the overall population highlight the importance of addressing stigma and discrimination not only specifically in the health sector but also in its causes and expressions in the society at large.

Summary: Why health workers discriminate

Several factors, often in combination, contribute to the stigma and discrimination that health workers may express towards patients. A major factor is incorrect and insufficient information, including about patients' rights, certain behaviors and populations, and diseases. Another cause is health workers' fear of contracting diseases, fears often exacerbated by misconceptions and misinformation, and by inadequate resources to ensure effective infection prevention and control. Stressful work environments, often heightened by as unsafe working environments and high patient loads, further fuel stigma and discrimination. So too do attitudes prevalent in the communities of which health workers are a part, and laws that criminalize certain behaviors that may lead health workers to violate patients' confidentiality.

4. The Right to Health and Patient Rights

⁴⁸ Center for Reproductive Rights & Federation of Women Lawyers - Kenya, *Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities* (2007). Available at: http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/pub_bo_failuretoddeliver.pdf.

The right to health: A brief overview - Many of the components of the right to health have been developed through legal frameworks of international declarations and treaties and national constitutions aiming to ensure fundamental rights for all individuals. The 1946 Constitution of the World Health Organization⁴⁹ and 1948 Universal Declaration of Human Rights⁵⁰ were the first international assertions of health as a fundamental human right. In 1976, the International Covenant on Economic, Social and Cultural Rights, with its guarantee of the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health,” came into effect.⁵¹ Two years later, the Declaration of Alma-Ata again declared health a fundamental right stating that individuals have the right to participate in their health decisions and that governments are responsible for ensuring the health of their people through the provision of adequate health and social measures.⁵²

The right to health covers both health care and underlying determinants of health such as adequate nutrition, clean water, adequate sanitation, and a healthy environment, addresses the essential elements of available, accessible, acceptable, and quality health services, goods, and facilities; key principles including non-discrimination and equality, participation, and accountability; includes core minimum components including essential primary health care for all; requires progressively achieving the full realization of this right and spending the maximum of available resources towards achieving this and other rights, and; includes international dimensions such as providing development assistance.⁵³ Well over 100 constitutions incorporate the right to health or to health care.⁵⁴

Patient rights - Rights that people have as patients, drawing on the right to health, are known as patient rights. To achieve the overall right to health, and to facilitate people in accessing health services, these are specific rights must be ensured for people when they seek health services. Health workers’ lack of awareness of the rights of patients, or inadequate policies to support patient rights, particularly when combined with people’s own lack of awareness of their rights, can lead to discrimination and inadequate provision of care. This is particularly so for vulnerable populations, who often face greater hurdles in achieving their rights. Policymakers, health workers, and patients need to be engaged and educated in patient rights. This should contribute to an increased standard of care and reduced levels of discrimination.

⁴⁹ Constitution of the World Health Organization Constitution (adopted July 1946, entered into force April 7, 1948), at preamble. Available at: http://www.who.int/governance/eb/who_constitution_en.pdf.

⁵⁰ Universal Declaration of Human Rights, G.A. res. 217A (III), U.N. Doc A/810 at 71 (1948), at art. 25. Available at: <http://www1.umn.edu/humanrts/instree/b1udhr.htm>.

⁵¹ International Covenant on Economic, Social and Cultural Rights, G.A. res. 2200A (XXI), 21 U.N.GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force Jan. 3, 1976, at art. 12. Available at: <http://www1.umn.edu/humanrts/instree/b2esc.htm>.

⁵² Declaration of Alma-Ata, adopted at the International Conference on Primary Health Care, Alma-Ata, USSR, September 6-12, 1978. Available at: http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf.

⁵³ International Covenant on Economic, Social and Cultural Rights, G.A. res. 2200A (XXI), 21 U.N.GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3, entered into force Jan. 3, 1976, at art. 12. Available at: <http://www1.umn.edu/humanrts/instree/b2esc.htm>; Committee on Economic, Social and Cultural Rights, *General Comment 14, The right to the highest attainable standard of health*, U.N. Doc. E/C.12/2000/4 (2000). Available at: <http://www1.umn.edu/humanrts/gencomm/escgencom14.htm>.

⁵⁴ Eleanor D. Kinney & Brian Alexander Clark, “Provisions for Health and Health Care in the Constitutions of the Countries of the World.” *Cornell International Law Journal* (2004) 37: 285-355, at 291, 305-355. Available at: http://indyaw.indiana.edu/instructors/Kinney/Articles/kinney_Constitutions.pdf.

Differing cultural, legal, and social frameworks in which these rights must apply and be implemented can lead to some variation in what are considered patients' rights.⁵⁵ There is, however, a broad consensus surrounding the inclusion of the rights to non-discrimination, informed consent, confidentiality, privacy, and information for all patients in health facilities worldwide.⁵⁶

The **right to non-discrimination** is violated by failing to provide care, by providing substandard care, or by abusing individuals based on characteristics such as disease status, gender, or ethnic background.⁵⁷ By directly or indirectly denying individuals access to quality health services, discrimination violates people's right to health. Individuals' right to life is also threatened when access to life-saving treatment such as anti-retroviral therapy - or, indeed, to prevention interventions that protect against contracting potentially lethal diseases - is obstructed.

The **right to informed consent**, rooted primarily in the rights to health and liberty of one's person,⁵⁸ is violated when a patient is tested for a condition without her knowledge, or is tested even after having refused the test. More broadly, health workers must obtain the patient's informed consent in order to administer testing, treatment, and other procedures, and before disclosing patient information. The right also addresses situations where a legal representative is required, and the importance of even in these circumstances of enabling patients to be involved in decision-making to the full extent that their capacity allows. Different facilities may have different procedures for obtaining consent, but these should align with the institutional and national policies in support of patient rights, which should in turn be consistent with international standards.⁵⁹

The **right to confidentiality** is meant to keep secure, and protect from disclosure without the patient's consent, data and other information about the patients and their health status. It is violated when health workers release the results of tests or other personal health information without the patient's knowledge. Data about patients and their health status should be kept secure and protected from disclosure without consent. This patient right to confidentiality obliges health workers to ensure that the information obtained about patients is only accessible to authorized parties and encourages health workers to take precautions to prevent patient information from being disclosed without the patient's permission. There may

⁵⁵ WHO, *A Declaration on the Promotion of Patients' Rights in Europe* (1994). Available at: http://www.who.int/genomics/public/eu_declaration1994.pdf.

⁵⁶ *Id.*; Committee on Economic, Social and Cultural Rights, *General Comment 14, The right to the highest attainable standard of health*, U.N. Doc. E/C.12/2000/4 (2000), at paras. 12(b), 18, 23. Available at: <http://www1.umn.edu/humanrts/gencomm/escgencom14.htm>.

⁵⁷ Discrimination is prohibited on the following grounds: "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health." Committee on Economic, Social and Cultural Rights, *General Comment 14, The right to the highest attainable standard of health*, U.N. Doc. E/C.12/2000/4 (2000), at para. 18. Available at: <http://www1.umn.edu/humanrts/gencomm/escgencom14.htm>.

⁵⁸ Lawyers Collective, *Consent*, <http://www.lawyerscollective.org/hiv-aids/activities/advocacy/issues-consent>, accessed July 12, 2010; Office of the UN High Commissioner for Human Rights & UNAIDS, *International Guidelines on HIV/AIDS and Human Rights, 2006 Consolidated Version* (2006), at 95-96. Available at: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf.

⁵⁹ See e.g., WHO, *A Declaration on the Promotion of Patients' Rights in Europe* (1994), at 11. Available at: http://www.who.int/genomics/public/eu_declaration1994.pdf

be very narrow exceptions to this right, such as in life-threatening emergencies, which should be clearly defined in law and policy.⁶⁰

Individuals should have the **right to privacy** in the health facility. A patient is entitled to physical discretion that respects their modesty and safety. Although this may be difficult in crowded health facilities especially in low-income countries where resources are scarce, measures should be taken to achieve the highest available standard of privacy. The patient right to privacy also extends to information and implies that patient have the right to decide what information they share with others regarding their health and other characteristics.⁶¹ In addition, patients should not be coerced into releasing or sharing information regarding their health or disease status.

Many health workers in Kenyan maternity facilities said that they were unsure to whom they should disclose HIV test, sometimes informing a woman's husband even when she had requested that he not be informed. The effects of revealing a woman's HIV-status without her permission can be devastating and far-reaching. Structural issues, such as the fact that two or more women often have to share a bed in maternity wards, also pose challenges to the rights to privacy and confidentiality.

Janet M. Turan, S. Miller, E.A. Bukusi, J. Sande, & C. R. Cohen, "HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services." *AIDS Care* (Sept. 2008) 20(8): 938-945, at 942

Releasing sensitive information about a patient, such as sexual orientation or identification with a marginalized group like commercial sex workers (CSW) or IDUs, similarly violates a patient's right to confidentiality while also increasing his or her vulnerability of experiencing stigma and discrimination in other sectors. The consequences can be severe, including imprisonment in countries where belonging to one of these groups is criminalized. The rights to health and to be free from inhumane treatment are violated if health workers physically or verbally abuse patients.⁶²

Further, individuals' **right to information** is violated when people are denied full and accurate information regarding their health and about proposed medical procedures and alternatives, access to their medical records, a second opinion, or the identification of the health workers providing their care. Other aspects of this right include the right to have information communicated to patients in ways that they can understand.⁶³

Health workers' lack of knowledge of these rights not only contributes to these violations, but itself indicates that the government has failed to meet its obligations under the right to health. The committee that the United Nations has charged with monitoring implementation

⁶⁰ WHO, *WHO Resources book on mental health, human rights, and legislation* (2005), at 32. Available at: <http://books.google.com/books?id=616HbUCHKyMC&lpg=PP1&pg=PR2>.

⁶¹ WHO, *A Declaration on the Promotion of Patients' Rights in Europe* (1994), at 10. Available at: http://www.who.int/genomics/public/eu_declaration1994.pdf.

⁶² Center for Reproductive Rights and Federation of Women Lawyers - Kenya. *Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities* (2007), at 79, 81. Available at: http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/pub_bo_failuretodeliver.pdf.

⁶³ WHO, *A Declaration on the Promotion of Patients' Rights in Europe* (1994), at 10. Available at: http://www.who.int/genomics/public/eu_declaration1994.pdf.

of this and other economic, social, and cultural rights has determined that the right to health includes certain “core obligations,” which must be adhered to under all circumstances and are not subject to progressive realization, as well as other “obligations of comparable priority.” The former include protecting access to health services on a non-discriminatory basis, and the latter include “appropriate training for health personnel, including education on health and human rights.”⁶⁴ To protect patients from abuse in the health sector, and to secure their rights, national and institutional laws and policies should provide for these rights and ensure that both health workers and people in general are educated about them.

Summary: Patient rights

Everyone has the right to “the highest attainable standard of physical and mental health.” Linked to and as part of this right, as well as other rights including the right to liberty of one’s person, exist what are known as patient rights. While the precise contours of these rights may vary across countries based on differing cultural, legal, and social frameworks, there is broad consensus on a number of patient rights. These include the rights to

- 1) non-discrimination;
- 2) informed consent;
- 3) confidentiality;
- 4) privacy, and;
- 5) information.

II. The Required Response

Interventions are needed at multiple levels to fully address and seek to eliminate health worker stigma and discrimination. Interventions that target and empower health workers and patients should be coupled with national and institutional policies that support patient rights. First, we examine how to develop and implement education and training sessions for health workers to reduce the stigmas that they might hold and the resulting discrimination.

1. Health Worker Interventions for Stigma Reduction

Education and training sessions should be conducted to empower health workers through knowledge, skills building, and sensitization exercises. Fundamental aspects of these trainings include participation by key stakeholders; a combination of didactic and active learning modules such as lectures, role-playing, and question and answer sessions; and reinforcement and reflection sessions. This combination of teaching techniques serves to accommodate different learning styles and to increase and reinforce knowledge, skills, and awareness. Lessons can be presented by trained facilitators in respected positions or trained peer educators, and should be conducted in a safe environment where all participants feel comfortable sharing their thoughts and experiences with others.

These interventions should be implemented during both pre-service and in-service training so that the greatest number of health workers can be targeted and lessons reinforced throughout a health worker’s career. The interventions as described below are tailored to the existing health workforce. However, the basic approaches and lessons are more broadly applicable, and could be adapted to pre-service training settings. Incorporating these

⁶⁴ Committee on Economic, Social and Cultural Rights, *General Comment 14, The right to the highest attainable standard of health*, U.N. Doc. E/C.12/2000/4 (2000), at paras. 43(a), 44(e). Available at: <http://www1.umn.edu/humanrts/gencomm/escgencom14.htm>.

exercises into pre-service training programs - and so reaching all new health workers - is a critically important aspect of a comprehensive effort to remove stigma and discrimination from the health workforce.

- **Participatory and inclusive approaches**

Early cooperation with and involvement of respected community leaders - and health facility leaders - is crucial to mobilize widespread support for stigma reduction interventions.⁶⁵ Community leaders, hospital management, health workers, and other health facility staff, as well as members of the very groups that experience stigma and discrimination, should be included in the design. This broad participation in designing interventions is important to develop programs within the relevant social and cultural contexts that are feasible and sustainable. The input of each group is needed so that relevant fears, misconceptions, and values can be taken into account. From these, activities can be designed to most effectively target the types and causes of stigma and discrimination and work to reduce their expression. In addition, this participatory approach creates consensus and ownership by those involved. This has been shown to increase efficacy of the interventions⁶⁶ and lead to long-term sustainability and expansion of interventions.⁶⁷

Interaction between stigmatized individuals and the health workers who express stigma and discrimination can lead to sensitization and decrease the prevailing “us” versus “them” attitude, which leads to mistreatment.

Laurie Blade (International Center for Research on Women), Best Practices for Stigma Reduction, Powerpoint presentation, SARDM on Stigma Workshop, New Dehli, India, Dec. 4, 2008, at slide 20. Available at: <http://siteresources.worldbank.org/SOUTHASIAEXT/Resources/223546-1192413140459/4281804-1231540815570/interventions.pdf>

Involvement of stigmatized individuals themselves in all aspects of the trainings is particularly important. One example of this high degree of participation can be found in a program to reduce HIV-related stigma and discrimination in Indian hospitals.⁶⁸ Existing training modules for health workers were supplemented with sensitization lessons and activities developed with local HIV/AIDS organizations and people with HIV/AIDS. The lessons were often presented by the same individuals who helped design them. Interaction between groups allows individuals to share and learn from each other’s experiences and also encourages the health facility staff to reflect on situations when they might have experienced shame, blame,

⁶⁵ Laura Nyblade, Khuat Thu Hong, Nguyen Van Anh, Jessica Ogden, Aparna Jain, Anne Stangl, Zayid Douglas, Nguyen Tao & Kim Ashburn (International Center for Research on Women & Institute for Social Development Studies), *Communities Confront HIV Stigma in Viet Nam: Participatory Interventions Reduce HIV Stigma in Two Provinces* (2008), at 28. Available at: <http://www.icrw.org/files/publications/Communities-Confront-HIV-Stigma-in-Vietnam.pdf>.

⁶⁶ Laura Nyblade, Khuat Thu Hong, Nguyen Van Anh, Jessica Ogden, Aparna Jain, Anne Stangl, Zayid Douglas, Nguyen Tao & Kim Ashburn (International Center for Research on Women & Institute for Social Development Studies), *Communities Confront HIV Stigma in Viet Nam: Participatory Interventions Reduce HIV Stigma in Two Provinces* (2008). Available at: <http://www.icrw.org/files/publications/Communities-Confront-HIV-Stigma-in-Vietnam.pdf>.

⁶⁷ D. Bajpai, S. Ghosh, R. Chandra, A. Yuvraj, G. Foster, P. Bhatt & J. Richardson, “Creating local participation for sustained results in community care and CABA programs in India.” 15th International Conference on AIDS, Bangkok, Thailand, July 11-16 2004, abstract no. ThPeD7801. Available at: <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102281570.html>.

⁶⁸ Vaishali S. Mahendra, Laelia Gilborn, Bitra George, et al. (Horizons Program, Sharan, Institute of Economic Growth), *Reducing AIDS-related Stigma and Discrimination in Indian Hospitals* (2006). Available at: <http://www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf>.

or other forms of discrimination themselves and how it affected them.⁶⁹ These activities should be conducted in a safe environment so that participants feel comfortable sharing their experiences. One approach to creating such an environment is to have the group facilitator share his or her own experiences first.

- **Participants and facilitators**

To create a stigma-free environment throughout the health facility, workers from each department should participate in stigma-reduction exercises. Even workers who do not provide direct care can express stigma and discrimination towards patients.⁷⁰ Program participants could include members from hospital management; physicians and nurses in leadership positions; other doctors, nurses, and clinicians; other health providers such as technicians and pharmacists; and hospital administration and support staff such as admission clerks, cafeteria workers, and security guards. Indeed, non-clinical staff such as guards and admission clerks may act as gatekeepers to a health facility; their mistreatment of stigmatized populations could lead to patients being turned away, denied care without even interacting with any health providers.

Due to the respect they already receive, people in authoritative positions within a health facility (or even the wider community) could be particularly effective in presenting the stigma-reduction lessons, after they themselves undergo training. For instance, the trainers in an intervention conducted in 1996 and 1997 to reduce AIDS-related stigma in several Nigerian health facilities were institutional leaders such as medical superintendents and chief lab technologists. They were considered to be role models by other staff members and successfully commanded respect.⁷¹ In an HIV/AIDS stigma reduction program in Indian hospitals, a session on the ethical and legal issues surrounding discrimination in the health facility was presented by a lawyer, a person with HIV/AIDS, and a human rights activist,⁷² an approach that would increase the legitimacy and acceptability of the information provided.

- **Understanding current stigma and discrimination among health workers**

Formal assessments can be used to better understand known stigmas or to directly interrogate the stigma that exists among health workers. These tools can gather baseline information regarding health worker perceptions to determine or refine understanding of specific areas that require attention in order to reduce stigma. An anonymous questionnaire distributed to staff can assess individual knowledge.

The International Center for Research on Women developed one such quiz, for example. It includes true and false questions to determine what participants know about HIV and AIDS.

⁶⁹ This participatory approach has been utilized by the International Center for Research on Women and is fully described in their 2006 toolkit developed to reduce HIV and gender-based violence stigma among health workers in India. Available at: <http://www.icrw.org/publications/reducing-hiv-stigma-and-gender-based-violence-toolkit-health-care-providers-india>.

⁷⁰ Khuat Thi Hai Oanh, Kim Ashburn, Julie Pulerwitz, Jessica Ogden & Laura Nyblade (Institute for Social Development Studies, International Center for Research on Women, Horizons Program), *Improving hospital-based quality of care in Vietnam by reducing HIV-related stigma and discrimination* (2008), at 16, 20. Available at: http://www.popcouncil.org/pdfs/horizons/Vietnam_HospitalStigmaReduction.pdf.

⁷¹ E.N.U. Ezedinachi, M.W. Ross, M. Meremiku, E.J. Essien, C.B. Edum, E. Ekure & O. Ita, "The impact of an intervention to change health workers' HIV/AIDS attitudes and knowledge in Nigeria: a controlled trial." *Public Health* (2002) 116: 106-112, at 107, 111.

⁷² Vaishali S. Mahendra, Laelia Gilborn, Bitra George, et al. (Horizons Program, Sharan, Institute of Economic Growth), *Reducing AIDS-related Stigma and Discrimination in Indian Hospitals* (2006), at 30. Available at: <http://www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf>.

Individuals are asked to respond to statements such as “HIV can be spread through sweat, urine, tears, and saliva” or “sex workers are largely responsible for spreading HIV.”⁷³

The answers provided during this evaluation should be kept confidential so that participants are aware of the safe, non-threatening environment, and feel comfortable sharing experiences and feelings. After determining the specific knowledge gaps and perceptions contributing to health worker attitudes of stigma, educational components of the intervention can be tailored to the specific needs of the health workers and their communities.

- **Educational components**

- Identify the problems of stigma and discrimination – From the beginning, it is important for participants to identify and understand the problem of stigma and discrimination. Its causes and effects on individuals and communities should be addressed. One successful technique is to have members of the stigmatized population(s) being addressed share their knowledge and experiences of discrimination.⁷⁴ A safe environment, where people are assured of the confidentiality of the discussions and that they face no risk of legal or social consequences if they discuss criminalized activity, is critical to ensure open, honest dialogue. The aim is to decrease fear and misunderstanding of stigmatized diseases and marginalized groups, and to sensitize health staff to the concerns of all patients. This also serves to decrease an attitude of “us” versus “them,” which can contribute to discrimination, as well as to mistrust between stigmatized populations and health workers.
- Accurate information – The training should include accurate disease, disability, and population information based on the knowledge gaps identified through the initial assessment. This might include information about how certain diseases are transmitted or proper techniques for universal precautions. Information about the characteristics and specific needs of vulnerable populations should be included, and again, can draw directly on the experiences and knowledge of individuals from these groups. For instance, different cultures often have varying beliefs about sexuality. Health workers should learn how to approach such issues in a culturally competent, non-judgmental manner using gender neutral terms, and learn to focus on behavior rather than sexual orientation in order to obtain accurate patient information and provide adequate care.⁷⁵

⁷³ Ross Kidd, Nandini Prasad, Jyothsna Avula, Mirza Tajuddin, Ramesh Ginni & Nata Duvvury (International Center for Research on Women & Bhoruka Public Welfare Trust), *Reducing HIV Stigma and Gender Based Violence: Toolkit for Health Care Providers in India* (2007), at 134. Available at: <http://www.icrw.org/publications/reducing-hiv-stigma-and-gender-based-violence-toolkit-health-care-providers-india>. This toolkit also suggested a group exercise where participants list fears about HIV/AIDS on note cards and post these under the headings “Fears” and “Myths” in front of the group. These are then discussed with the group, questions answered, and misinformation countered. Sample responses include fears related to “[g]etting HIV from clients” and to “dying slowly, painfully, and alone,” while myths could include “AIDS only affects sex workers and truck drivers” and “[u]sing condoms makes women barren.” *Id.* at 116.

⁷⁴ P.L. Hall & N. Tarrier, “The cognitive-behavioural treatment of low self-esteem in psychotic patients: a pilot study.” *Behaviour Research & Therapy* (2003) 41: 317-332.

⁷⁵ Kaiser Permanente, *A provider’s handbook on culturally competent care: lesbian, gay, bisexual and transgender population* (2nd edition) (2007).

- Understanding patients' rights – Stigma-reduction programs should seek to increase the respect of patients' rights and dignity. Training should directly address human rights.⁷⁶ Health workers should understand international and national rights and standards and the particular policies to which they should adhere. Training can remind staff members who are also health professionals of their profession's credo, which supports the rights of patients, outlines the responsibilities of health workers, and prescribes service free from discrimination. And all program participants, including those who are not health professionals, can be reminded of the values, goals, and mission of the health sector (and as relevant, of the individual health facility), the shared responsibility of all health workers including non-clinical staff to contribute to the mission and goals, and how stigma and discrimination undermine them. Again, it could be useful to include the participation of individuals whose rights have been violated to explain how they felt and how it affected the care they received, and possibly how it affected them beyond the health care context.
- Responding to patient needs/Community services – Health workers might be unaware of the links between ill health - including stigmatized diseases and the health of stigmatized populations - and people's economic and legal situations. Or health workers might not know the role they can have in helping their patients receive support for their non-medical needs. It is important that health workers be informed of these connections and of the community services and organizations that provide legal or social support for vulnerable patients. Health workers should also be educated on when and how to refer patients to these services. Health workers can then direct patients in need to appropriate services. These might include legal services for women with HIV/AIDS and survivors of violence or support groups for people with mental illness.
- Enhancing understanding and acceptance – Participants should have the opportunity to question and compare the information provided with their own experiences and inherent beliefs. This will facilitate health workers in understanding and accepting this information. This can be done through large group discussions, breakout sessions, or focus groups. A variety of methods are included in the training manuals listed in the resources section at the end of this guide. In addition, "report back" sessions can be conducted following breakout sessions to further reinforce information and address lingering questions.⁷⁷
- Post-intervention evaluation and follow-up – Health staff should be evaluated on their knowledge and attitudes towards patients with the stigmatized characteristics that the training addressed. This helps ensure intervention effectiveness, including by revealing any shortcomings that can be addressed by altering the intervention in the

⁷⁶ A review of an intervention to reduce stigma against people with HIV/AIDS among Nigerian health workers found that improvements in the perception of people with HIV/AIDS "was probably related to the explicit emphasis on issues of discrimination and human rights in the intervention," as well as providing scientific and clinical information. E.N.U. Ezedinachi, M.W. Ross, M. Meremiku, E.J. Essien, C.B. Edum, E. Ekure & O. Ita, "The impact of an intervention to change health workers' HIV/AIDS attitudes and knowledge in Nigeria: a controlled trial." *Public Health* (2002) 116: 106-112, at 111.

⁷⁷ See, e.g., Ross Kidd, Nandini Prasad, Jyothsna Avula, Mirza Tajuddin, Ramesh Ginni & Nata Duvvury (International Center for Research on Women & Bhuruka Public Welfare Trust), *Reducing HIV Stigma and Gender Based Violence: Toolkit for Health Care Providers in India* (2007), at 129, 131. Available at: <http://www.icrw.org/publications/reducing-hiv-stigma-and-gender-based-violence-toolkit-health-care-providers-india>.

future. The evaluation can also determine whether any knowledge gaps still persist among participants that will need to be filled.

Some interventions attempt short-term follow-up evaluations and have shown that positive outcomes have endured. Very few, if any, interventions have included long-term monitoring and evaluation, mainly due to lack of funding. Yet to ensure a sustained stigma-free environment in the health facility and provision of adequate care to all patients, long-term follow-up should be conducted. This should be done along with training of new employees and, as needed, additional interventions to reinforce previous trainings, address shortcomings in earlier actions that may emerge, and respond to new information and changing conditions. This will serve to reinforce widespread competent, non-discriminatory care and sustain program successes.

Addressing the complexities of stigma: compounded stigma and self-stigma

Stigma and discrimination can manifest in complex ways. These might require variations on the interventions outlined in this guide. A person with multiple stigmatizing characteristics may experience “compounded stigma.” Examples include being HIV-positive and being a member of a marginalized group such as IDU, CSW, or an ethnic minority. Because of the complex nature of compounded stigma, interventions that target stigma and discrimination toward multiple characteristics are rare. However, stigmas have common foundations and some organizations report the potential to develop interventions that address stigma and discrimination toward multiple groups, such as by combining lessons to reduce HIV/AIDS stigma with lessons concerning stigma expressed toward CSW, IDU, or ethnic minorities.

In addition, health workers who belong to stigmatized groups may experience self-stigma. Targeting self-stigma often requires not only eliminating the expression of stigma and discrimination, but also increasing an individual’s self-esteem through support groups or counseling.

Kit Yee Chan, Yi Yang, Kong-Lai Zhang, Daniel D. Reidpath, “Disentangling the stigma of HIV/AIDS from the stigmas of drug use, commercial sex and commercial blood donation - a factorial survey of medical students in China.” *BMC Public Health* (2007) 7(280). Available at: <http://www.biomedcentral.com/1471-2458/7/280>; Ruth C. White & Robert Carr, “Homosexuality and HIV/AIDS stigma in Jamaica.” *Culture, Health & Sexuality* (July-Aug. 2005) 7(4): 347-359. Available at: http://ruthcwhite.com/Sample_Publications_files/Carr%26White.pdf; Personal communication with Laura Nyblade, Director, Stigma, Discrimination, and Gender Portfolio, International Center for Research on Women, April 30, 2009; E.S. Krishnamoorthy, “Treatment of depression in patients with epilepsy: problems, pitfalls, and some solutions.” *Epilepsy & Behavior* (2003) 4 (Supp 3): S46-S54

Kit Yee Chan, Yi Yang, Kong-Lai Zhang, Daniel Reidpath. Disentangling the stigma of HIV/AIDS from the stigmas of drug use, commercial sex, and commercial blood donation - a factorial survey of medical students in China. *BMC Public Health* (2007) 7(280).

Summary: Health worker interventions to reduce stigma

All health workers should receive, through pre-service and in-service programs, training and sensitization to reduce and prevent stigma and discrimination, and ensure respect for patient rights. The trainings themselves should be designed through an inclusive approach, with health workers, civil society organizations, and community members including those who belong to stigmatized populations participating in developing the interventions. Formal assessments can also be used to help determine which stigmas need to be addressed. People belonging to the stigmatized groups that are the focus of the interventions should be involved not only in the planning, but also in the trainings themselves. All health workers, including support staff, should participate in the trainings, which should be participatory (such as including discussions and role-playing).

In general, components of the training should include identifying and understanding the problem of stigma and discrimination, providing accurate information, educating health workers on patient rights, providing health workers the knowledge and skills needed to connect patients to community services, and comparing the information and experiences provided in the training with health workers' own beliefs. The trainings should be evaluated for their effectiveness, including longer-term evaluations if possible.

2. Structural Interventions for Stigma Reduction

To reinforce and complement health worker stigma-reduction training, structural adjustments should be made in health facilities to enable health workers to provide quality care for all and create a stigma-free environment.

- Adequate supplies must be available. Health workers have cited lack of adequate supplies and proper facilities to treat and care for patients as a reason to deny or delay the provision of care. For instance, maternity workers in Kenya have reported avoiding or delaying necessary procedures for HIV-positive women, and not wanting to help them deliver, especially in the absence of an adequate glove supply.⁷⁸ Another study in Nigeria found that only 72% of health workers practice universal precautions in all cases. Of those who did not, 65% reported a lack of resources as the reason for not practicing universal precautions in all cases. This contributed to health workers' discriminatory behavior.⁷⁹ Health facilities should provide sufficient stock of necessary materials such as drugs, gloves, syringes, needle disposal bins, and hand washing stations that enable health workers to provide quality care and practice universal precautions. Having the proper tools to care for patients regardless of disease status decreases health worker fear of contracting disease and being stigmatized for being associated with patients who have the stigmatized condition. Proper tools also reduce the risk that health workers might inadvertently spread disease through the reuse of syringes or other materials. In a study conducted in September 2003 in Ogun State, Nigeria, health workers were significantly more willing to provide services to

⁷⁸ Janet M. Turan, S. Miller, E.A. Bukusi, J. Sande, & C.R. Cohen, "HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services." *AIDS Care* (Sept. 2008) 20(8): 938-945, at 943.

⁷⁹ Physicians for Human Rights, *Nigeria: access to health care for people living with HIV/AIDS* (2006), at 25, 44, 52. Available at: <http://physiciansforhumanrights.org/library/documents/reports/nigeria-access.pdf>

individuals with HIV/AIDS when gloves were provided for their use.⁸⁰ Countries should also establish policies to use safe injection devices, such as retractable syringes, which maximize safety for health workers and patients alike.⁸¹

Along with enabling health workers to provide care that is safe for themselves and their patients, facilities should be accessible and safe for all patients, providing necessary accommodations for people with disabilities and private spaces for patient consults, exams, and counseling. Also, health managers should also attend to the physical and psychosocial health needs of health workers, as caring for the health workers can encourage and enable health workers to be caring towards their patients.⁸²

- Procedures and policies should ensure privacy and accountability. Discriminatory practices including using distinguishing marks such as writing “HIV+” on a patient’s chart should be prohibited. So too should segregating patients within a health facility based on disease status, unless isolation is medically necessary and recommended practice to prevent the spread of the disease, such as for infectious tuberculosis and Ebola haemorrhagic fever.⁸³ Conversely, innovative steps that can reduce stigma may be discovered and adapted. These may improve provider-patient interactions or even counter stigma in the broader community, even in small ways, through the health care setting. For example, as part of an intervention in Vietnam to address stigma and discrimination against people with HIV/AIDS, chairs were placed in hospital waiting rooms to increase patient socialization and foster solidarity among the HIV-positive and HIV-negative patients.⁸⁴
- Health workforce policies should support patient care. Employing a diverse health workforce with members that can identify with the populations being served can make patients feel more comfortable seeking care.⁸⁵ For instance, both female and male

⁸⁰ A.E. Sadoh, A.O. Fawole, W.E. Sadoh, A.O. Oladimeji & O.S. Sotiloye, “Attitude of health-care workers to HIV/AIDS.” *African Journal of Reproductive Health* (April 2006) 10(1): 39-46. Available at: <http://ajol.info/index.php/ajrh/article/viewFile/7874/1501>.

⁸¹ Retractable syringes are currently more expensive than other auto-disable syringes, which can be used only once but lack the same level of protection for health workers. However, as they become more widely used and the economies of scale take effect, their price is decreasing and will continue to approach the same price as other single use syringes. Personal communication, Jorge Mancillas, health services officer, Public Services International, Feb. 1, 2010.

⁸² For example, Pranakorn-Sri-Ayutthaya Hospital in Ayutthaya, Thailand, has an extensive program to ensure the health and safety of health workers, including health worker check-ups, health education programs, fitness programs, and more, and actively monitors and seeks to improve employee satisfaction. Powerpoint presentation by hospital’s human resource management to Board of the Global Health Workforce Alliance, Jan. 31, 2010, Ayutthaya, Thailand.

⁸³ WHO, U.S. Centers for Disease Control and Prevention & International Union Against Tuberculosis and Lung Disease, *Tuberculosis Infection Control in the Era of Expanding HIV Care and Treatment: Addendum to WHO Guidelines for the Prevention of Tuberculosis in Health Care Facilities in Resource-Limited Settings, 1999* (2006), at 40. Available at: http://www.who.int/tb/publications/2006/tbhiv_infectioncontrol_addendum.pdf; U.S. Centers for Disease Control and Prevention & WHO, *Infection Control for Viral Haemorrhagic Fevers in the African Health Care Setting* (1998), at Section 3: Isolate the Patient. Available at: <http://www.cdc.gov/ncidod/dvrd/spb/mnpages/vhfmanual.htm>.

⁸⁴ Khuat Thi Hai Oanh, Kim Ashburn, Julie Pulerwitz, Jessica Ogden & Laura Nyblade (Institute for Social Development Studies, International Center for Research on Women, Horizons Program), *Improving hospital-based quality of care in Vietnam by reducing HIV-related stigma and discrimination* (2008), at 18. Available at: http://www.popcouncil.org/pdfs/horizons/Vietnam_HospitalStigmaReduction.pdf.

⁸⁵ See, e.g., P. Crawford & B. Brown, “Like a friend going round: reducing the stigma attached to mental healthcare in rural communities.” *Health and Social Care In The Community* (2002) 10: 229-238; UK Department of Health, *Delivering race equality in mental health care: An Action Plan for reform inside and outside services and*

health workers could be employed at reproductive health centers so that both female and male clients feel comfortable seeking services and sharing medical history and sexual health information. All staff should wear identification badges so that patients can obtain information easily and identify staff members when needed.⁸⁶ Knowing that they can be readily identified and thus held to account for any discriminatory or other inappropriate behavior could be an incentive for health workers to respect patients and their rights.

Summary: Structural interventions to reduce stigma

Health facilities, services, and policies should be developed and supported in ways that will help reduce stigma and discrimination. This includes ensuring health worker and patient safety, such as by ensuring sufficient supplies and training to ensure an effective infection prevention and control regime. Facilities should include accommodations for people with disabilities and private spaces for patient consults, exams, and counseling. Discriminatory practices, such as segregating HIV+ patients, should be prohibited. Health workforce policies should also be designed to contribute to respect for all patients, including by promoting a diverse workforce and having all staff where identification badges.

3. Reducing Stigma by Empowering Patients

Patients should be informed of their rights and the mechanisms available to secure them. To facilitate a stigma-free health environment, patients should receive comprehensive information in a safe, easily understood manner, and be directed to services that support their well-being.

- **Comprehensive information must be provided.** For a patient to be empowered to make health decisions, she must receive comprehensive information about her health and available treatments in a manner that is easily understood. This should include a discussion between the health worker and patient about the nature of the patient's health condition, proposed and alternate treatment options, the risks and benefits associated with treatments, and an assessment of patient knowledge regarding her health. This will help ensure that patients are able to make informed decisions regarding their care.⁸⁷ Patients should be encouraged to ask questions and any

the Government's response to the independent inquiry into the death of David Bennett (2005), at 25-26, 42 (addressing the need for ethnic diversity in the health workforce and for the health workforce to be representative of local groups). Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4100773;

Center for Reproductive Rights and Federation of Women Lawyers - Kenya. *At risk: rights violations of HIV-positive women in Kenyan health facilities* (2008), at 31 ("Women living with HIV can be particularly effective counsellors for those seeking HIV treatment and testing by creating a supportive environment that can encourage and facilitate the testing and treatment of other women and by sharing their experiences about the realities of living with the virus."). Available at:

<http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/At%20Risk.pdf>.

⁸⁶ Center for Reproductive Rights & Federation of Women Lawyers - Kenya, *Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities* (2007), at 30, 89. Available at:

http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/pub_bo_failuretodeliver.pdf.

⁸⁷ University of Washington School of Medicine, *Informed Consent: Ethical Topic in Medicine*, <http://depts.washington.edu/bioethx/topics/consent.html>, accessed July 30, 2010.

discussions about medical care should be addressed empathetically. This interaction between patient and health worker will build trust and create a relationship conducive to sustained, adequate care. It should also create an environment where the patient feels safe and is well-positioned to and understands the need to comply with treatments.⁸⁸

When health workers discriminate against or otherwise mistreat patients, patients may feel vulnerable, powerless to make decisions, and coerced into undergoing a course of care that they actually do not want.

- Patients should be made aware of their rights. Often, individuals or health workers are unaware of the right to health or patient rights or national policies to uphold them, contributing to violations of these rights. Community members will be less likely to be deterred from seeking health care and more empowered when visiting a health facility if they understand their rights. For example, women who experienced mistreatment at maternal health facilities in Kenya often wanted to complain, but did not know their rights or how to address their grievances. They were not fully aware of policies to support their rights.⁸⁹

As detailed below, a description of patient rights, including the right to health and supportive policies (e.g., if health services or a certain set of health services are free at the point-of-services) along with information regarding what to do if patients feels their rights have been violated, should be readily available and prominently displayed throughout the health facility through posters, brochures, or other media, and produced in a language easily understood by patients. These rights should also be conveyed to the public through the media, such as newspapers and the radio. It is important that information about these rights is accessible by all people, including those who are illiterate.

In a 2001 study of patient rights in Turkey, only 9% of respondents reported being aware of patient rights regulations. Of those who reported experiencing violations of their rights, 75.3% reported that their health provider failed to introduce themselves while 95.2% reported never having received any written information from their provider.

N. Kuzu, A. Ergin & M. Zencir, "Patients' awareness of their rights in a developing country." *Public Health* (April 2006) 120(4): 290-296

- Patients should be directed to outside services, if needed. To further support a patient's right to quality care and the highest attainable standard of health, health workers should direct patients to relevant support groups, counseling services, and legal services, where available. These can assist patients in coping with their health situation, improve their care, and protect them from unnecessary burdens outside of the health sector. For example, cognitive behavioral interventions provided in health facilities have been shown to increase self-esteem, improve stress management, and

⁸⁸ M.L. Heijnders, "Experiencing leprosy: perceiving and coping with leprosy and its treatment. A qualitative study conducted in Nepal." *Leprosy Review* (Dec. 2004) 75(4): 327-37.

⁸⁹ Center for Reproductive Rights and Federation of Women Lawyers - Kenya. *Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities* (2007), at 71-72. Available at: http://reproductiverights.org/sites/crr.civicactions.net/files/documents/pub_bo_failuretoddeliver.pdf.

reduce fear experienced by individuals with severe mental illness and epilepsy.⁹⁰ Support groups can improve the attitude of patients, health workers, and community members, and have been shown to decrease social isolation, improve patients' response toward diagnosis, decrease misconceptions about stigmatized diseases, and promote adherence to treatment.⁹¹ Support groups and counseling can also increase people's self-esteem, which will often be required to address self-stigma.⁹²

It might also be necessary to direct patients to legal services, such as if they have experienced domestic violence. Health workers should also be able to refer patients to other social services, such as to provide nutritional support, educational opportunities, or income-generation programs, as well as government social welfare programs.

Summary: Reducing discrimination by empowering patients

Patients should be empowered to exercise their rights. This requires, firstly, that patients be informed on the right to health and on patient rights, as well as mechanisms in place to secure these rights. These rights should be prominently displayed at health facilities as well as disseminated through the media and other channels. Health workers should provide patients comprehensive information that patients need to make health decisions, and in ways that they can easily understand. Health workers should direct patients to relevant support groups, counseling services, and legal services, as well as other social services, such as nutrition and education programs.

4. The Role of Policymakers in Developing a Health Sector in Which Patient Rights Are Respected

As those directly accountable for protecting and fulfilling the right to health government policymakers have a particular responsibility to eliminate discrimination from the health sector and ensure that patient rights are respected. Policymakers from various ministries, including health, finance, justice, and education (particularly for ensuring the issues of human rights and patient rights are incorporated into pre-service curricula), as well as parliamentarians and local officials, all have roles to play.

⁹⁰ E.S. Krishnamoorthy, "Treatment of depression in patients with epilepsy: problems, pitfalls, and some solutions." *Epilepsy & Behavior* (2003) 4 (Supp 3): S46-S54; P.L. Hall & N. Tarrier, "The cognitive-behavioural treatment of low self-esteem in psychotic patients: a pilot study." *Behaviour Research & Therapy* (2003) 41: 317-332.

⁹¹ M. Demissie, H. Getahun & B. Lindtjorn, "Community tuberculosis care through 'TB clubs' in rural North Ethiopia." *Social Science & Medicine* (2003) 56: 2009-2018; Family Health International, Nursing Care of Patients with HIV/AIDS: Session 14: Helping the Patient Understand and Adhere to ART, Powerpoint presentation (c. 2008), at slide 35. Available at: <http://www.fhi.org/training/en/HIVAIDS/NCPGuide/flash/14.swf>; P.R. Alencastro, N.E. Hamester & F.A. Maciel, "The importance of a support group in improving adherence." 14th International Conference on AIDS, Barcelona, Spain, July 7-12, 2002, abstract no. ThPeF8191. Available at: <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102254099.html>.

⁹² E.S. Krishnamoorthy, "Treatment of depression in patients with epilepsy: problems, pitfalls, and some solutions." *Epilepsy & Behavior* (2003) 4 (Supp 3): S46-S54; Jean Macq, Alejandro Solis, Guillermo Martinez & Patrick Martiny, "Tackling tuberculosis patients' internalized social stigma through patient centred care: An intervention study in rural Nicaragua." *BMC Public Health* (2008) 8 (154). Available at: <http://www.biomedcentral.com/1471-2458/8/154>.

- **Understanding the current stigma and discrimination**

What stigmas require action to address them? Certain stigmas - such as those against people with HIV/AIDS or people with disabilities - may be well known globally or in particular regions or countries. In such cases, policymakers and health authorities should further assess the extent of these stigmas in their countries' health sector and, as needed, develop interventions, such as those discussed elsewhere in this guide. Members of a stigmatized group might themselves bring information about stigma to the attention of health authorities or other policymakers. These concerns must be assessed and addressed. NGO, media, or other reports might also raise issues of health sector stigma requiring intervention. For instance, a report from the Federation of Women Lawyers-Kenya and the Center for Reproductive Rights identified severe human rights abuses against women in Kenya's largest maternity hospital, and the Kenyan government's failure to respond. Another report by the same organizations documented human rights abuses of HIV-positive women seeking health care in Kenya.⁹³

- **Funding for stigma reduction interventions**

Governments and development partners should ensure that stigma-reduction intervention programs are allocated enough funding to implement multiple, effective, and sustained interventions covering the entire health sector, and to monitor and evaluate these interventions. This entails adequate funding for a full range of interventions required to reduce stigma and discrimination in the health sector, including the structure interventions and health worker trainings described above. It also requires support for appropriate policies - such as incorporating anti-stigma modules into pre-service training curricula and effective infection prevention and control policies - in the first place.

- **Domesticating the right to health**

Governments must enact laws and develop and enforce policies that domesticate and detail the right to health, including by creating the legal infrastructure that supports respect for patients' rights and dignity. These laws and policies should be developed through a transparent, participatory process, promote the rights of all individuals, and ensure accountability at individual institutions and through government structures. They should detail government obligations under this right, and develop the policies and means of enforcing these policies. Here we focus on one aspect of the right to health, patient rights, which involve how people are treated when they interact with the health sector.

- **Patient rights: Charters, institutional policies and enforcement**

Policymakers should establish processes to develop patient right charters, and to ensure the enforcement of these rights.

⁹³ Center for Reproductive Rights and Federation of Women Lawyers - Kenya. *Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities* (2007). Available at: http://reproductiverights.org/sites/crr.civicactions.net/files/documents/pub_bo_failuretodeliver.pdf; Center for Reproductive Rights and Federation of Women Lawyers - Kenya, *At Risk: Rights Violations of HIV-Positive Women in Kenyan Health Facilities* (2008). Available at: <http://reproductiverights.org/sites/crr.civicactions.net/files/documents/At%20Risk.pdf>.

- Patient rights charter

Countries should use participatory processes - such as national and regional forums, meetings with civil society, and opportunities for written and electronic input - to develop a charter of patient rights. The charter should be consistent with and incorporate relevant elements of the right to health. Patient rights to incorporate into the charter include the rights to confidentiality, privacy, information, informed consent, and freedom to choose their treatment and their provider. Preferably, the charter will also explicitly recognize and provide basic information on the right to health itself, as does, for example, the Australian Charter of Healthcare Rights.⁹⁴ Information on what to do if these rights are violated should be readily available as well, whether as part of the charter or separately.

Patient rights charters should be written in easily understood language and be clearly and prominently advertised to increase patient awareness, as well as health worker accountability for respecting them. Health facilities should prominently post this declaration of patient rights. Depending on the needs of the populations being served, the charter may need to be posted in local as well as national language(s) to ensure its genuine accessibility. Along with being posted in health facilities, they should be disseminated through print and other media, including media that is most accessible by people who are illiterate and do not speak the country's dominant language. Health facilities should have policies in place that ensure health workers are provided with patient rights training and the means to disseminate this information to the communities they serve.

- Complaint mechanisms

As part of the accountability that the right to health requires, individuals should have the means to submit grievances if they believe that their rights have been violated. This will enable them to obtain proper redress, should increase the accountability of health workers, and can be used to monitor quality of care over time.

The relevant authorities should develop policies on complaint mechanisms where such policies are not yet in place, and health facilities and other institutions, such as professional regulatory bodies, should implement these policies. Health facilities and health ministries, cooperating with civil society, the media, and other relevant entities (such as national human rights commissions and local governments), should ensure that information regarding the process is readily available and accessible to all.

Patients (as well as staff) should be allowed to submit comments and complaints free of cost and confidentially, to ensure that they face no risk of retaliation. Possible mechanisms for reporting grievances include complaint boxes placed in the health facility, mailing in complaint forms to health facility management or governing bodies, or submitting complaints online. The proper mechanism will depend on the infrastructure available, yet it should always be readily accessible, easy to use, and well advertised to all patients and visitors. The health facility management or other relevant authorities should acknowledge and affirm receipt of all complaints.

Investigation into complaints should be fair, comprehensive, and timely. Those investigating the complaints must be unbiased. If the investigation determines that someone's rights were

⁹⁴ Australian Commission on Safety and Quality in Healthcare. *Australian Charter of Healthcare Rights* (2008). Available at: [http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/4DC8258009C0CD48CA257753001EDB84/\\$File/17537-charter.pdf](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/4DC8258009C0CD48CA257753001EDB84/$File/17537-charter.pdf).

violated, proper relief should be provided promptly. This may include, as appropriate, compensation to the patient, rehabilitation for the harm caused (such as by providing further health, legal, or other social services), sanctions for the health worker including revoking the health worker's license, and structural remedies to prevent future violations of patient rights.⁹⁵ Structural remedies may include developing clearer guidelines on confidentiality, changing policies to better protect informed consent, improving monitoring and evaluation procedures, and providing health workers with additional training on human rights, including patient rights.

Moreover, effective complaint process can do even more than improving adherence to patient rights through the outcomes of individual complaints. The awareness that the complaints create about certain problems and negative trends can lead health workers and government officials to identify and address common problems. As a Kenyan midwife said, "The more women who get the complaints in the right ear, the better services will become."⁹⁶

The South African Department of Health developed a Patient Rights Charter aimed at upholding the National Constitution's guarantee of the "right of access to health care services." The South African Department of Health recommends that the charter is placed in noticeable locations and be written in the local languages to increase comprehension by the population being served. The South African Charter includes a list of patient responsibilities, notably holding patients responsible for respecting the rights of other patients.

The mechanisms to ensure access to quality health services are derived from legislation and the national Constitution. The 2003 South African National Health Act 61 requires all provincial governments and municipal councils to develop formal complaints system, and that the complaint procedures be listed near the entrance of each health facility and be communicated to users regularly. Complaints about doctors and nurses can be filed with the relevant training and licensing authorities. The National Health Act also established the National Office of Standards Compliance and an Ombudsperson which is charged with receiving complaints regarding health services. In addition, complaints can be reported to the courts, to quasi-judicial organizations such as the South African Human Rights Commission (SAHRC), or through a telephone hotline service. In addition, the provinces monitor complaint history and responses over time and can include civil society in this process as well. Even as there have been recommendations to make the South African system stronger, the complementary nature of multiple mechanisms to submit grievances and provide redress increases the opportunities to ensure that individuals' right to non-discriminatory, respectful health services.

World Bank, *Realizing Rights through Social Guarantees: An Analysis of New Approaches to Social Policy in Latin America and South Africa* (Feb. 2008), at 61-63, 67. Available at: <http://siteresources.worldbank.org/EXTSOCIALDEV/Resources/3177394-1168615404141/3328201-1192042053459/SouthAfrica.pdf?resourceurlname=SouthAfrica.pdf> [pages 7-9, 13]

South Africa's Patient Rights Charter is available at: http://www.capegateway.gov.za/eng/pubs/public_info/P/3162

South Africa's National Health Act 61 is available at: <http://www.info.gov.za/view/DownloadFileAction?id=68039>

⁹⁵ For an overview of types of remedies that may be provided when an individual's right to health is violated, see Helen Potts. *Accountability and the Right to the Highest Attainable Standard of Health* (2008), at 28-29. Available at: http://www.essex.ac.uk/human_rights_centre/research/rth/docs/HRC_Accountability_Mar08.pdf.

⁹⁶ Center for Reproductive Rights and Federation of Women Lawyers - Kenya. *Failure to Deliver: Violations of Women's Human Rights in Kenyan Health Facilities* (2007), at 71. Available at: http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/pub_bo_failuretodeliver.pdf.

- Collaboration with civil society and human rights institutions

Collaboration with civil society or others can improve the effectiveness of complaint mechanisms. Civil society organizations or ombudspersons (who typically receive their mandate from the government, especially from national human rights institutions) often serve as mediators in handling complaints, supporting the patient's rights, helping the patient navigate the process, and providing unbiased guidance during discussion between parties. This is especially important if the individuals and organizations investigating complaints utilize a self-regulation process without outside oversight, such as a medical association that regulates and upholds standards of medical practice and ethics but also aims to protect the practitioners who are members of the association.⁹⁷

- Community structures

Policymakers should support communities in developing effective structures that monitor local health services and can effectively respond to violations of patient rights, including by ensuring that measures necessary to prevent future violations are implemented. Such structures may include village health committees, health center boards, or structured community-based monitoring (such as through routine patient and health worker interviews and facility observations). These structures should include the participation of both community members and health workers. Along with helping monitor patient rights and respond to non-compliance, these structures can more be engaged in designing, monitoring and evaluating, and helping redress shortcomings with respect to local health services, including how they conform to the right to health and specific policies to implement this right, as well as how they meet particular community needs.

- Monitoring grievances

A logbook that anonymously lists the complaints received and their outcomes should be kept in health facilities, and by external groups if applicable, to monitor how grievances change over time and provide transparency on how the rights of patients are being enforced. Publishing a complaint log can increase accountability of health workers and encourage health facilities to utilize feedback to continue doing what works well, change what is not working, and improve provision of services.

- Examples of policy implementation and enforcement structures

Countries can take a variety of approaches to defining patient rights and developing the structures to uphold them. One possibility is to have a single overarching national policy that defines patient rights, ensures awareness of and respect for patient rights, and offers mechanisms for redress. This policy should be developed with the input of health workers, patient advocates, civil society including human rights organizations, and community members. Health facilities would then adopt this policy, adapting it as needed depending on the characteristics of each facility.

For example, the Australian National Mental Health Policy sets out national criteria to be followed by mental health service facilities across Australia, as well as recommendations for monitoring how well these criteria are being met.⁹⁸ These standards were developed in compliance with national legislation as well as international standards such as the UN Principles on the Protection of People with a Mental Illness and Improvement in Mental Health

⁹⁷ *Id.*, at 68-69, 88. Available at:

http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/pub_bo_failuretodeliver.pdf.

⁹⁸ Commonwealth of Australia, *National Standards for Mental Health Services* (1997). Available at:

<http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-servstds-toc>.

Care⁹⁹ to ensure that they support respect for patient rights and the optimal quality of life for people with mental illness.

Countries could also develop a set of national criteria regarding patient rights and proper redress that health facilities would be required to meet through their own institutionally-established protocols. In Guyana, for instance, a National Policy Document on HIV/AIDS was revised in 2006 and laid out specific rights that people with HIV/AIDS are entitled to as well as the respective roles of the Ministry of Health and individual health entities. The national policy leaves it to individual health organizations to develop policies on the confidentiality of employees with HIV/AIDS, and also advises that each institution develop its own confidentiality statements and policies. The Ministry of Health is charged with developing a mechanism “to receive, investigate and act on complaints on breaches of confidentiality.”¹⁰⁰

Policies and processes may be decentralized to the province or municipal level, such as in the South African approach cited above, where the National Health Act requires each provincial government and municipal council to develop a formal complaint system for the areas of the national health system for which they are responsible.¹⁰¹ Another possible approach would be to have a national law or policy that requires both public and private facilities to adopt their own patient rights and redress policies based on national criteria that ensure that the individual facility approaches fully protect patient rights. To ensure that the facilities comply, developing these policies can be a condition of licensing. Civil society, including marginalized populations and organizations representing health system users, and health workers should have the opportunity to have a voice in choosing which of these approaches to take, or to develop other avenues for ensuring that patient rights are defined, protected, and monitored.

In determining the approach, policymakers and others involved in making the decision should be guided by the goal of most effectively eliminating stigma and discrimination from the health sector and securing patient rights, and the right to health more broadly. Factors to consider include whether

- a more decentralized approach will allow for greater participation in determining rights and mechanisms to secure them, and would be better tailored to diverse populations across the country;
- there exists the local capacity to assume the primary capacity in defining and ensuring these rights;
- a more national approach will better ensure consistency with international human rights standards;
- in some areas there is a risk that a decentralized approach risks being undermined by local prejudices, and;

⁹⁹ Principles for the Protection of Persons with Mental Illnesses and the Improvement of Mental Health Care, G.A. res. 46/119, 46 U.N. GAOR Supp. (No. 49) at 189, U.N. Doc. A/46/49 (1991). Available at: <http://www1.umn.edu/humanrts/instree/t2pppmii.htm>.

¹⁰⁰ Ministry of Health, Guyana National AIDS Programme Secretariat. 2006. Revised National Policy Document on HIV/AIDS in Guyana, at 9 (confidentiality). See also *id.* at 13 (rights and responsibilities). http://hivaidsclearinghouse.unesco.org/search/resources/nac_po_revisedaidspolicy.pdf.

¹⁰¹ World Bank, *Realizing Rights through Social Guarantees: An Analysis of New Approaches to Social Policy in Latin America and South Africa* (Feb. 2008), at 61-63, 67. Available at: <http://siteresources.worldbank.org/EXTSOCIALDEV/Resources/3177394-1168615404141/3328201-1192042053459/SouthAfrica.pdf?resourceurlname=SouthAfrica.pdf> [pages 7-9, 13]; South Africa, National Health Act No. 61 of 2003 (assented to by the President July 18, 2004), at sec. 18. Available at: <http://www.info.gov.za/view/DownloadFileAction?id=68039>.

- a national approach or more decentralized approach will best facilitate publicizing information on patient rights and enforcement mechanisms.

Summary: Patient charters and other roles policymakers in reducing discrimination

Policymakers - including in health, finance, justice, and education ministries, parliamentarians, and local officials - should actively seek to address stigma and discrimination, including in the health sector. They should respond vigorously when civil society organizations or others raise concerns about stigma and discrimination. They should ensure that adequate funding is available to support the training, policy development and implementation, health worker and patient safety, and other interventions required for an effective and comprehensive strategy to eliminate stigma and discrimination from the health sector. Policymakers should also develop laws and policies to domesticate and ensure the right to health, with laws and policies detailing the ways that the government will afford and enforce this right.

As one piece of the effort to ensure the right to health, policymakers should drive the process of establishing patient rights charters. These should be developed through a participatory process and describe in accessible language patient rights including to non-discrimination, confidentiality, privacy, informed consent, and information, as well as the right to health and its major implications in the country context. Charters should be disseminated widely, including through the media and being prominently displayed at health facilities, including in local languages. They may be developed at national level or through a more decentralized approach that is guided by national criteria. Country should develop and disseminate information on compliant mechanisms, which should be free to access and provide redress, which may include sanctioning health workers, compensating victims of abuse, and developing structural remedies to avoid future violations of patient rights. Processes should be established to help people access these mechanisms. Governments should support communities in developing effective structures for monitoring local health services, including with respect to patient rights, and should respond to identified shortcomings.

5. Addressing Discrimination Outside the Health Sector

- **A national response to stigma and discrimination**

To fully combat stigma and discrimination and support an individual's right to high quality health services, health sector specific interventions will need to be complemented by measures to address these scourges within the entire society. The primary responsibility for developing and taking these measures rests with the government. Yet as with the response to stigma in the health sector, enabling stigmatized groups to help design these broader responses is critical to their success. These groups can highlight specific needs and ensure that the response takes their concerns fully into account. Since discrimination often unfolds at the local level, and because of the importance of changing norms to reducing and ultimately eliminating stigma, community leaders will also be critical to the response.

- **Ensuring a non-discriminatory and rights respecting legal infrastructure**

Countries should enact laws and policies that ensure the equal rights of and prohibit discrimination against women, people living with AIDS, people with disabilities, and other people on the basis of their nationality, religion, disease status, sexual orientation, or other

prohibited grounds of discrimination.¹⁰² These laws, regulations, and other policies should eliminate any vestiges of discrimination that exist in current criminal and civil codes or in government policies. And lawmakers and other officials must avoid introducing new laws or policies that exacerbate rather than remove discrimination. They should ensure effective enforcement mechanisms and incorporate processes for monitoring and evaluating them, and for adjusting the policies to address shortcomings and build on successes. Civil society organizations, including those comprised of and representing the needs of marginalized populations, and health workers should be fully involved in developing these laws and policies.

Through government and civil society efforts, under the government's stewardship, judges, lawyers, police, and other legal and law enforcement personnel understand these prohibitions against discrimination and fully enforce these laws in their respective roles. Particularly due to the stigma that may impede enforcement of these laws, or cause people to be reluctant to bring violations of their rights to non-discrimination to the attention of the authorities (including for fear that their claims will not be listened to or for fear of retaliation), community leaders must also be educated and sensitized to the importance of non-discrimination and people's legal rights. The government, in close collaboration with civil society organizations, community leaders, and the media, should launch vigorous public awareness campaigns to ensure that people know their rights - and the rights of others in their communities and countries.

The government should fund legal services programs and other institutions, such as human rights commissions and ombudspersons, to help people secure their rights. These services must be meaningfully accessible to people who have suffered from discrimination, including, for example, at affordable cost (which may require that these services be free of charge) and being advertised through and with personnel who speak local languages. Meaningful redress, including compensation for victims, sanctions for perpetrators, and structural remedies, must be provided when people are discriminated against.

And just as particular policies must be developed for the health sector, countries will need to devise policies addressing stigma and discrimination in employment, housing, the education system, and other sectors.

- **Addressing health sector stigma through measures beyond the health sector**
Along with addressing stigma in a society-wide fashion, and through legal and policy measures specific to other sectors, specific measures beyond the health sector will be required to enable people to access health services without discrimination.

- **Community awareness**

Broad-based community awareness campaigns can build awareness about health-related issues, people's right to health - including to non-discrimination within the health sector - and spread messages about available health resources and the impacts of stigma on the

¹⁰² The International Covenant on Economic, Social and Cultural Rights prohibits "any discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health." Committee on Economic, Social and Cultural Rights, *General Comment 14, The right to the highest attainable standard of health*, U.N. Doc. E/C.12/2000/4 (2000), at para. 18. Available at: <http://www1.umn.edu/humanrts/gencomm/escgencom14.htm>.

community. This education may include how preventing certain people from receiving quality health services, such as denying men who have sex with men or injecting drug users HIV-related services, can accelerate the spread of disease, endangering the health of everyone. These campaigns may also reach individuals who are prevented from seeking health services due to the perceived threat of stigma and discrimination, informing them of their rights and the institutions and processes that can help secure them. The media should be engaged in such campaigns to the fullest. Often, members of the media themselves will need to be sensitized to issues of stigma and discrimination.¹⁰³ Government, civil society, and community leaders all also have important roles in these community campaigns.

- Law enforcement and public officials

Individuals should not be discouraged from obtaining necessary health services for fear of being arrested, detained, or harassed by law enforcement officials. It is therefore important to work with police officers and other law enforcement officials to protect the rights of individuals who are seeking health services, even if they are participating in unlawful activities. Countries should develop policies to ensure that law enforcement activities will not obstruct health-seeking activities. Officials need to be engaged, educated, and empowered to understand and respect the rights of all individuals, and indeed, to be sensitized to accept people with stigmatized conditions.¹⁰⁴ Practices such as detaining injecting drug users outside needle and syringe programs - which are critical to preventing the spread of HIV and other bloodborne infections - must end.

- Education systems

Human rights education, including on the right to health, should be provided to all health workers, including support staff. These should include pre-service and in-service lessons that have been shown to decrease stigmatizing attitudes and actions.¹⁰⁵ Other sectors should also include human rights components in their education and training programs. Creating a greater understanding of people's rights should lead to improved health services and better health outcomes.

¹⁰³ Ute Ritterfeld & Seung-A Jin, "Addressing Media Stigma for People Experiencing Mental Illness Using an Entertainment-Education Strategy." *Journal of Health Psychology* (March 2006) 11(2): 247-267; A. Ukil, "Media role in stigma reduction in West Bengal villages." 15th International Conference on AIDS, Bangkok, Thailand, July 11-16, 2004, abstract no. ThPeD7904. Available at:

<http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102281668.html>.

¹⁰⁴ V. Pinfeld, "Working with the police." Presented at Together Against Stigma conference, Leipzig, Germany, Sep. 2-5, 2001.

¹⁰⁵ See, e.g., R. Mukherjee, A. Fialho, A. Wijetunge, K. Checinski, & T. Surgenor, "The stigmatisation of psychiatric illness: The attitudes of medical students and doctors in a London teaching hospital." *Psychiatric Bulletin* (2002). 26: 178-181. Available at: <http://pb.rcpsych.org/cgi/reprint/26/5/178>; Graham Thornicroft, Elaine Brohan, Aliya Kassam & Elanor Lewis-Holmes, "Reducing Stigma and Discrimination: Candidate Interventions." *International Journal of Mental Health Systems* (2008) 2:3, at 3-4. Available at: <http://www.ijmhs.com/content/pdf/1752-4458-2-3.pdf>.

Summary: Addressing stigma and discrimination outside the health sector

Eliminating the impact of stigma and discrimination on people's right to health will require interventions beyond the health sector. Policymakers must develop, through a participatory process, a legal infrastructure that is free from and prohibits discrimination, protects patient rights, and acts against stigma. They must ensure that laws and regulations prohibit discrimination in general and in the health sector in particular, and repeal and reform laws and policies as needed to create this non-discriminatory legal framework. They must also ensure that legal and law enforcement personnel understand and enforce these laws, while working with civil society and community leaders to promote enforcement and ensure that people have access to legal services to protect their rights.

Government, community leaders, and civil society should collaborate in developing community awareness campaigns, which can often be supported by the media. Law enforcement and public officials must be educated on people's rights to be free from discrimination, and end policies that could obstruct people's rights, such as obstructing people's efforts to seek health services. The health sector, and other sectors, should incorporate human rights into their training programs.

Resources

1. HEALTH WORKER STIGMA INTERVENTION MATERIALS

Reducing Stigma and Discriminated Related to HIV and AIDS: Training for Health Care Workers - This is a comprehensive training manual developed by EngenderHealth. It is designed for conducting a two-day course.

Source: EngenderHealth, *Reducing Stigma and Discriminated Related to HIV and AIDS: Training for Health Care Workers* (2004). Available at: http://www.engenderhealth.org/files/pubs/hiv-aids-stis/reducing_stigma_trainer_English.pdf

Understanding and Challenging HIV Stigma: Toolkit for Action - This toolkit was developed through a series of workshops in Ethiopia, Tanzania, and Zambia. It is designed for participatory learning, and for collective learning and action. Users of this guide are encouraged to use the exercises relevant to their setting and needs, and not necessarily work through the full guide.

Source: Ross Kidd & Sue Clay (CHANGE Project & International Center for Research on Women), *Understanding and Challenging HIV Stigma: Toolkit for Action* (2003). Available at: <http://www.icrw.org/publications/understanding-and-challenging-hiv-stigma-toolkit-action>

Reducing HIV Stigma and Gender Based Violence: Toolkit for Health Care Providers in India - This toolkit is a guide for trainers of health care workers with exercises aimed at preventing HIV/AIDS transmission and reducing stigma and other barriers to seeking care and disclosing HIV status, as well as sensitizing health workers to gender-based violence and helping them respond to it. Trainers are able to choose the “learner-centered, participatory” exercises most pertinent to the health care workers they are targeting.

Source: Ross Kidd, Nandini Prasad, Jyothsna Avula, Mirza Tajuddin, Ramesh Ginni & Nata Duvvury (International Center for Research on Women & Bhoruka Public Welfare Trust), *Reducing HIV Stigma and Gender Based Violence: Toolkit for Health Care Providers in India* (2007). Available at: <http://www.icrw.org/publications/reducing-hiv-stigma-and-gender-based-violence-toolkit-health-care-providers-india>

STEP (Stigma Elimination Programme) - This intervention, which began in March 2002 in Nepal, used a participatory approach and increased social participation by individuals with leprosy. Ten people living with epilepsy were chosen to act as facilitators and organize self-help groups in the community. These groups came to incorporate credit unions and micro-enterprise activities and expanded their membership to individuals from other marginalized and disadvantaged groups.

Source: Hugh Cross & Ramesh Choudhary. “STEP: An intervention to address the issue of stigma related to leprosy in Southern Nepal.” *Leprosy Review* (2005) 76: 316-324. Available at: <http://69.175.94.114/~leprahea/lr/Dec05/Lep316-324.pdf>

Nigerian health worker AIDS attitude intervention - This intervention used participatory methods involving members of at-risk populations and training respected individuals to be the intervention leasers.

Source: E.N.U. Ezedinachi, M.W. Ross, M. Meremiku, E.J. Essien, C.B. Edum, E. Ekure & O. Ita, “The impact of an intervention to change health workers’ HIV/AIDS attitudes and knowledge in Nigeria: a controlled trial.” *Public Health* (2002) 116: 106-112

HIV-related health worker stigma reduction in China - This intervention consulted with community advisors and used a participatory approach.

Source: Sheng Wu, Li Li, Zunyou Wu, Li-Jung Liang, Haijun Cao, Zhihua Yan & Jianhua Li, "A brief HIV stigma reduction intervention for service providers in China." *AIDS Patient Care & STDs* (June 2008) 22(6): 513-520

HIV-related community stigma reduction in Vietnam - This intervention, conducted from 2005 to 2007, worked with community leaders and members in two provinces in Vietnam to reduce HIV/AIDS stigma. Activities included sensitization workshops with authorities and representatives from social organizations, workshops for community members to develop their own action plans, community implementation of action plans with technical assistance, and monitoring and evaluation of program activities.

Source: Laura Nyblade, Khuat Thu Hong, Nguyen Van Anh, Jessica Ogden, Aparna Jain, Anne Stangl, Zayid Douglas, Nguyen Tao & Kim Ashburn (International Center for Research on Women & Institute for Social Development Studies), *Communities Confront HIV Stigma in Viet Nam: Participatory Interventions Reduce HIV Stigma in Two Provinces* (2008). Available at: <http://www.icrw.org/files/publications/Communities-Confront-HIV-Stigma-in-Vietnam.pdf>

HIV-related health worker stigma and discrimination reduction in Vietnam - This intervention used a participatory approach and included all levels of staff in the intervention.

Source: Khuat Thi Hai Oanh, Kim Ashburn, Julie Pulerwitz, Jessica Ogden & Laura Nyblade (Institute for Social Development Studies, International Center for Research on Women, Horizons Program), *Improving hospital-based quality of care in Vietnam by reducing HIV-related stigma and discrimination* (2008). Available at: http://www.popcouncil.org/pdfs/horizons/Vietnam_HospitalStigmaReduction.pdf

WHO Global campaign against epilepsy - This campaign incorporated interventions to reduce stigma, educate health workers, increase prevention, and expand treatment for persons living with epilepsy.

Available at: http://www.who.int/mental_health/management/globalepilepsycampaign/en/

Reducing AIDS-related Stigma and Discrimination in Indian Hospitals - This intervention used a participatory approach and sensitization exercises.

Source: Vaishali S. Mahendra, Laelia Gilborn, Bitra George, et al. (Horizons Program, Sharan, Institute of Economic Growth), *Reducing AIDS-related Stigma and Discrimination in Indian Hospitals* (2006). Available at: <http://www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf>

Combating HIV stigma in health care settings: what works? - This article covers many of the issues addressed in the present guide.

Source: Laura Nyblade, Anne Stangl, Ellen Weiss & Kim Ashburn (International Center for Research on Women), "Combating HIV stigma in health care settings: what works?" *Journal of the International AIDS Society* (2009) 12:15. Available at: <http://www.jiasociety.org/content/12/1/15>

2. PATIENT RIGHTS AND RESPONSIBILITY CHARTERS

Israel Patient's Rights Act, 1996 – A list of patient rights for those seeking medical care.
Available at: <http://waml.haifa.ac.il/index/reference/legislation/israel/israel1.htm>

American Hospital Association Patient Care Partnership – A plain language brochure available in multiple languages that explains the rights and responsibilities of patients in American hospitals.
Available at: <http://www.aha.org/aha/issues/Communicating-With-Patients/pt-care-partnership.html>

American Psychiatric Association et al., Mental Health Bill of Rights Project
Available at: <http://www.healthyminds.org/Main-Topic/Patient-Bill-of-Rights.aspx>

Australian Charter of Healthcare Rights – A one-page, easily understood explanation of rights of people using the health system.
Available at:
[http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/4DC8258009C0CD48CA257753001EDB84/\\$File/17537-charter.pdf](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/4DC8258009C0CD48CA257753001EDB84/$File/17537-charter.pdf)

South Africa's Patients' Rights Charter – A list of patient rights and responsibilities.
Available at: http://www.capegateway.gov.za/eng/pubs/public_info/P/3162

3. HEALTH WORKER RIGHTS AND RESPONSIBILITY CHARTERS

Rights and Responsibilities of Health Workers, Hungary, 1997
Available at:
http://www.szozolo.hu/53/rights_and_obligations_of_healthcare_workers.htm

4. COMPLAINT MECHANISMS

US Department of Health and Human Services – this website allows individuals who believe their health information privacy rights were violated to submit complaints to the Office for Civil Rights.
Available at: <http://www.hhs.gov/ocr/privacy/hipaa/complaints/index.html>

Minnesota Department of Health – includes searchable database of past complaints and resolutions.
Available at: <http://www.health.state.mn.us/divs/fpc/ohfinfo/filecomp.htm>

South Africa complaint mechanism – information on complaint procedures and structures available through a World Bank analysis.
Source: World Bank, *Realizing Rights through Social Guarantees: An Analysis of New Approaches to Social Policy in Latin America and South Africa* (Feb. 2008), at 61-63, 67.
Available at: <http://siteresources.worldbank.org/EXTSOCIALDEV/Resources/3177394-1168615404141/3328201-1192042053459/SouthAfrica.pdf?resourceurlname=SouthAfrica.pdf> [pages 7-9, 13].

5. COMMUNITY AWARENESS AND MEDIA CAMPAIGNS

Media and community partnership in stigma reduction in Nigeria. - This stigma-reduction intervention created a partnership between media personalities, people living with HIV/AIDS, community members, and care providers. The integrated approach sought to increase the visibility of people living with HIV/AIDS and promoted interaction and problem solving among groups.

Source: O.O. Akanni, J.H. Danuk, O.A. Falobi & M. Nwagwu, “Media and community partnership in stigma reduction in Nigeria.” 15th International Conference on AIDS, Bangkok, Thailand, July 11-16, 2004, abstract no. MoPeE4041. Available at: <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102280325.html>

Alaska Mental Health Trust Authority – Includes a variety of communication material on reducing stigma related to mental disabilities.

Available at: <http://www.mhtrust.org/index.cfm?section=Communications&page=Media-Campaigns>