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REDUCING STIGMA AND DISCRIMINATION TO MEET HIV-POSITIVE WOMEN'S REPRODUCTIVE HEALTH NEEDS IN KENYA

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EXECUTIVE SUMMARY

From 2008–2009, the USAID | Health Policy Initiative, Task Order 1, carried out an activity in Kenya aimed at reducing stigma and discrimination (S&D) by healthcare providers related to HIV-positive women's family planning (FP)/reproductive health (RH) needs. This activity reflected recent data indicating that 57.9 percent of HIV-positive women have an unmet need for family planning in Kenya (NASCOP, 2009). In addition, many HIV-positive women report provider hostility and judgmental attitudes when they reveal they are sexually active and would like information about family planning or when they become pregnant. Similarly, many Kenyans believe that an HIV-positive woman should not be sexually active (Center for Reproductive Rights and FIDA, 2008).

This activity built on existing RH/HIV integration efforts undertaken by the national RH/HIV Integration Committee, supported by the Ministry of Public Health and Sanitation and Ministry of Medical Services. The Health Policy Initiative recognized that, in the context of RH/HIV integration in Kenya, there is a need to reduce stigma and discrimination by healthcare providers of HIV-positive clients. Furthermore, with both HIV and RH service delivery sites offering increased services in both arenas, it is important to ensure that providers are knowledgeable and up-to-date on FP/RH options and services for HIV-positive clients.

To start, the project gathered data on HIV-positive clients' experiences related to FP/RH and on healthcare providers' knowledge and beliefs regarding HIV and services for HIV-positive women. The assessment revealed that while HIV-positive women understand family planning in general, they often have misconceptions due to lack of information or inaccurate information from healthcare providers. Misconceptions limit women's contraceptive options (e.g., emphasis is on condom use); might deter FP use or treatment (e.g., misunderstanding the interaction between FP methods and antiretroviral treatment); and affect childbearing decisions. Furthermore, HIV-positive pregnant women may stop attending HIV clinics when they become pregnant and go to general antenatal clinics where their status is not known, compromising their overall care. Discussants reported high levels of stigma and discrimination in maternal and child health/FP clinics and maternity wards, in comparison with comprehensive care clinics. Less than half of providers report being trained on FP/RH services for HIV-positive clients, revealing a potential lack of knowledge that can affect access to and quality of care and information for HIV-positive women. While the majority of providers believe people living with HIV (PLHIV) have the right to receive FP/RH counseling, nearly one-third of providers reported that they do not counsel HIV-positive clients on FP/RH.

Based on the findings, the Health Policy Initiative and in-country partners decided to create a training module on HIV-positive women's reproductive health needs and S&D issues. To guide the activity, the RH/HIV Integration Committee formed a Stigma and Discrimination Taskforce comprising a subset of its members and other stakeholders in the service provision sector. The project worked with taskforce members to design and test an S&D training module with RH and HIV service providers. Those developing the module drew on existing training resources on the issue, adapting them to fit the Kenyan context. After a pilot-test and revision of the module, the committee endorsed the final versions of the *Stigma and Discrimination in Reproductive Health and HIV: An Orientation Module for Health Workers, Trainer's Manual* and the accompanying participant's manual. The module covers the following theme areas: basic facts about RH and HIV; thoughts, beliefs, and attitudes related to HIV and AIDS; aspects of stigma and discrimination and their effects; ethical issues related to S&D; and facility action planning. The module will soon be available for inclusion in larger training efforts around FP/RH and HIV, such as national integration activities.

This experience revealed a need for both FP/RH and HIV providers, in the context of integrated services, to be trained on stigma and discrimination. Working with a national integration committee that took

ownership of the issue, the module was quickly developed to fit the Kenyan context. Key steps in the process included

- Assessing existing resources related to S&D and HIV-positive women's needs for FP/RH;
- Conducting interviews with FP providers and focus groups with members of support groups and networks of PLHIV, including both women and men, to discuss their S&D experiences in the context of accessing FP information and services;
- Sharing the findings with the RH/HIV Integration Committee and later with a wider group of stakeholders;
- Establishing a taskforce to guide the process of training module development, pre-test, and finalization;
- Adapting existing training curricula on S&D into a module that includes family planning for a training-of-trainers for FP providers; and
- Pre-testing and revising the training module.

The process initiated in this activity demonstrates Kenya's commitment to ensuring HIV-positive women's access to FP/RH services. The training module developed under the RH/HIV Integration Committee will aid those providing these services in a non-stigmatizing and non-discriminatory manner. Healthcare providers would also benefit from up-to-date, periodic training on FP/RH issues and options for HIV-positive women. Such training would serve to increase their knowledge on the types of family planning options that are appropriate for HIV-positive women, which would also benefit PLHIV, who have expressed a desire to learn more about family planning and reproductive health.

The initiative of the committee's Stigma and Discrimination Taskforce has shown that organizations and the government can work together for a specific purpose. The RH/HIV Integration Committee is currently doing a final review of the training module. Crucial to rolling out the training module will be further support of the Ministry of Public Health and Sanitation and Ministry of Medical Services to integrate the module with existing training programs.

ABBREVIATIONS

ACK	Anglican Church of Kenya
AIDS	acquired immunodeficiency syndrome
AMWOF	Assalam Muslim Women Forum
AMREF	African Medical and Research Foundation
ANC	antenatal care
ART	antiretroviral treatment
CCC	comprehensive care centers
DRH	Division of Reproductive Health
FIDA	Federation of Women Lawyers-Kenya
FP	family planning
HIV	human immunodeficiency virus
ITWG	Integration Technical Working Group
KAIS	Kenya AIDS Indicator Survey
KETAM	Kenya Treatment Access Movement
MCH	maternal and child health
MOMS	Ministry of Medical Services
MOPHS	Ministry of Public Health and Sanitation
NASCOP	National AIDS/STI Control Program
NEPHAK	National Empowerment Network of People Living with HIV/AIDS in Kenya
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
RH	reproductive health
S&D	stigma and discrimination
STI	sexually transmitted infection
UDPK	United Disabled Persons of Kenya
UNAIDS	Joint United Nations Program on HIV/AIDS
USAID	United States Agency for International Development
VCT	voluntary counseling and testing

I. BACKGROUND

Family Planning and Reproductive Health Services for HIV-Positive Women

"Reproductive health is a state of complete physical, mental, social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and freedom to decide if, when, and how often to do so."

—The 1994 International Conference on Population and Development, Programme of Action

According to the 2008 global report of the Joint United Nations Program on HIV/AIDS (UNAIDS), women account for half of the 33 million adults living with HIV, with nearly 60 percent of HIV infections in sub-Saharan Africa (UNAIDS, 2008). Most HIV-positive women are over age 15 (UNAIDS, 2008), meaning they are in their childbearing years and may be sexually active. Like all women, HIV-positive women have the right to be sexually active and need to be able to access high-quality, non-discriminatory family planning and reproductive health (FP/RH) information and care. However, recent research indicates that HIV-positive women's reproductive health is often overlooked (Kyomuhendo and Kiwanuka, 2008; Eckman et al., 2006).

Many HIV-positive women report healthcare provider hostility and judgmental attitudes regarding desires for family planning (POLICY Project, 2006). Healthcare providers often believe that HIV-positive women should not be sexually active (Kyomuhendo and Kiwanuka, 2008). When FP/RH services are offered, providers frequently limit the number of options for HIV-positive women (Kyomuhendo and Kiwanuka, 2008). This may be due to a lack of clear information and guidelines on which services are appropriate for HIV-positive women or a manifestation of stigma and discrimination. Providers themselves are part of broader communities where there may be societal stigma and discrimination toward people living with HIV (PLHIV), especially toward sexually active HIV-positive women who are considering whether to have, delay, or not have children.

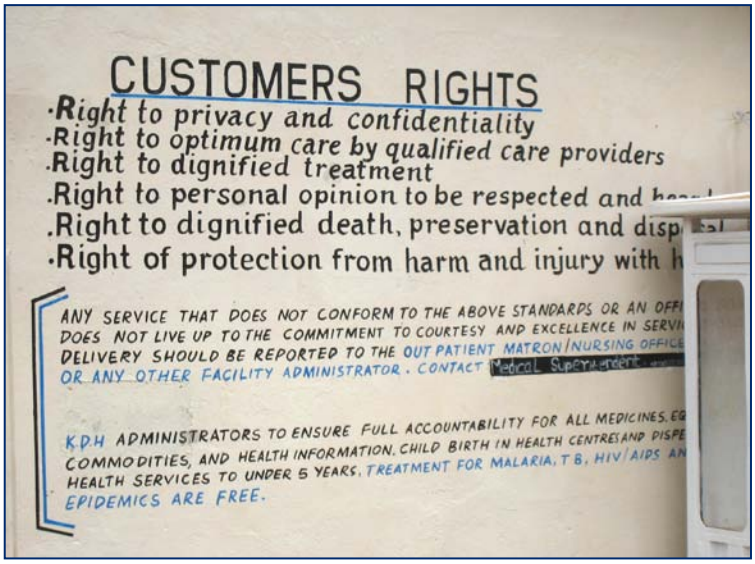
For these reasons, HIV-positive women's unmet need for contraception is high and often times greater than that of women in the general population. For example, in Uganda, the Centers for Disease Control and Prevention reported that 93 percent of pregnancies among pregnant women receiving antiretroviral treatment (ART) were unintended (Cohen, 2008). Similarly, research by Family Health International on women in HIV counseling and testing clinics (where women are at high risk for HIV) revealed that the majority of women said that they did not want another child in the next two years. In Kenya, it was 59 percent, 66 percent in Tanzania, and 77 percent in Zimbabwe (Cohen, 2008).

HIV-Positive Women in Kenya

The recent Kenya AIDS Indicator Survey (KAIS) estimates that 1.42 million (7.1%) adults (ages 15–64) are HIV positive, with HIV prevalence being higher among women (8.4%) than men (5.4%) (NASCOP, 2009). Likewise, of adults of reproductive age (15–49), 8.8 percent of women and 5.5 percent of men are HIV positive (NASCOP, 2009). This variation changes with age. Among young women, prevalence rises as age increases and by age 24, women are 5.2 times more likely to be HIV positive than men of the same age (12% versus 2.3%) (NASCOP, 2009). In addition, young women (ages 15–34) are more likely to be positive compared with young men in the same age group (NASCOP, 2009). Women in these age ranges are typically sexually active and are important clients of FP/RH information and care.

In Kenya, more than half (57.9%) of HIV-positive women (ages 15–49) in married or cohabiting relationships who express a need for family planning are not using any contraception (NASCOP, 2009). Women living with HIV are more likely to not be using any contraception (57.9%) than women who are HIV negative (51.8%) (NASCOP, 2009). They are also less likely to be using modern contraception (40.5% versus 45.6%, respectively) (NASCOP, 2009). These data reflect research that revealed HIV-positive Kenyan women's desire for more information on the best FP methods for them to use, along with complaints from FP and antenatal care (ANC) clinic clients about the quality of care, specifically stigma and discrimination and uncaring and insensitive providers at government health clinics (Gichuhi et al., 2004).

A recent study indicates that many Kenyans believe HIV-positive women should not be sexually active (Center for Reproductive Rights and FIDA, 2008). Healthcare providers who share this belief are often biased against HIV-positive women and demonstrate negative attitudes toward them. Women report being reprimanded for bearing children or being sexually active; and being denied access to contraception, family planning information, and maternity services (Center for Reproductive Rights and FIDA, 2008). This discrimination may increase HIV-positive women's risk of unintentionally conceiving or transmitting HIV to their partners and children (Center for Reproductive Rights and FIDA, 2008).



Customers' rights listed on the wall of the Kerugoya District Hospital. December 2008.

Research reveals an ongoing need to address stigma among health workers, including addressing the root causes. The 2005 Kenya Health Workers Survey reported that understaffing and other constraints in their work environment has resulted in pressure on healthcare providers, who may not be aware of their negative behaviors (NASCOP, 2006). For example, many providers may be working in facilities that lack infection control measures, resulting in a fear of HIV infection (NASCOP, 2006). For this reason, the Kenya Health Worker Survey recommended that efforts to reduce stigma should be coupled with tangible improvements in infection control. In addition, strong efforts should be made to sensitize health workers about confidentiality, violations of patient rights, and the need to respect the dignity of patients (NASCOP, 2006). There may also be a need to develop supportive structures so that patients and others who experience stigma and discrimination can seek assistance (NASCOP, 2006).

RH/HIV Integration in Kenya

The Kenya National HIV/AIDS Strategic Plan for 2005/6–2009/10 provides the framework for the country's current response to HIV and AIDS.[1] The plan's priority areas include improving the quality of life of people living with and affected by HIV and AIDS, with an objective of improving treatment and care and protecting rights and access to effective services (NASCOP, 2009). In this context, Kenya's Ministries of Health—the Ministry of Public Health and Sanitation (MOPHS) and Ministry of Medical Services (MOMS)—have initiated the integration of FP and HIV services.

[1] On January 10, 2010, Kenya launched the Third National AIDS Strategic Plan (2010–2013).

Kenya's second National Health Sector Strategic Plan II supports the integration of FP and HIV services to provide effective and accessible services to as many people as possible. As such, Kenya has been working to integrate FP and HIV services by making FP services available in HIV clinics and testing sites and by making HIV prevention, care, and treatment services available in FP clinics. Initially, integration efforts had been project-based, with little being done to address barriers to sustainable RH/HIV integration within government systems. In response, in 2007, the USAID | Health Policy Initiative, Task Order 1, conducted a barriers analysis to identify and rank policy and operational barriers to integration of FP and HIV services (Okundi et al., 2009). Through interviews with policymakers, program managers, and service providers, the assessment identified numerous barriers, including the lack of service protocols and operational policy guidelines to support integration, inadequate governmental funding for FP/HIV integration, limited staffing levels in public health facilities, and the existence of parallel HIV and FP/RH supervision and logistics systems. The project presented the study findings at a one-day workshop where key stakeholders categorized the barriers into eight issue areas (see Box 1). Participants subsequently decided to create a subcommittee to work on an integration strategy and guidelines to address the barriers. The group also agreed to expand the Integration Working Group, which was established in 2002 to support a pilot study for integrating FP and voluntary counseling and testing (VCT) services.

Box 1. Operational Support Barriers to RH/HIV Integration

- Integrated service delivery
- Services for males and youth
- Coordination and supervision
- Infrastructure
- Staffing
- Logistics and commodity supply
- Reporting format and supply collection.
- Financing

As part of the Integration Technical Working Group's (ITWG) expansion, its mandate was broadened to include the range of FP/RH and HIV services, resulting in a multisectoral ITWG. The ITWG is co-chaired by the National AIDS/STI Control Program (NASCOP) under MOMS and the Division of Reproductive Health (DRH) under MOPHS and has more than 30 members, including government and United Nations agencies, nongovernmental organizations, private sector organizations, cooperating agencies, and donor agencies. It is responsible for establishing mechanisms to achieve the integration of FP/RH and HIV services at both the policy and operational levels. The working group's objective is to facilitate the scale-up of FP/RH/HIV service integration by ensuring that supportive policies and guidelines are in place, harmonizing planning, and preventing stockouts. The group is also expected to advocate for integration, securing the resources and political commitment necessary to make it a reality. The Health Policy Initiative facilitated the group's initial expansion and strengthened it by providing technical support and information. The project also helped the group clearly outline its purpose and objectives, assisted in ensuring funding for the group, and supported its leadership to attend high-level conferences to build their capacity. As a result of the project's efforts, the ITWG is now firmly established within the government and has access to the Minister of Health. It coordinates all work on integrating FP/RH and HIV services. Last, and most important, the ITWG also ensures that materials and activities are contextually correct and appropriate for Kenya.

Based on the results of the rapid assessment of barriers to FP/RH/HIV integration in Kenya, the ITWG decided to focus on the creation of an RH/HIV integration strategy. To manage this process, the ITWG formed a separate, smaller subcommittee called the RH/HIV Integration Committee. The Health Policy Initiative headed the subcommittee and provided technical and financial support for drafting of the National RH/HIV Integration Strategy. The goal of the strategy is to increase access to high-quality, affordable RH and HIV services. The strategy recognizes that RH and HIV services share similar characteristics, target populations, and desired outcomes, and that, therefore, clients seeking HIV services and RH services share common needs and concerns. The subcommittee, led by the Health Policy Initiative, and the ITWG oversaw the development and finalization of the strategy, which was approved

by the DRH and NASCOP in May 2009. Plans are underway to formally launch and disseminate the strategy this year.

II. PROJECT ACTIVITIES

Project Design

In the context of strengthening RH/HIV integration efforts around the world, addressing stigma and discrimination has become increasingly important. To improve the delivery of integrated services, the Health Policy Initiative designed an intervention focusing on addressing and reducing stigma and discrimination by healthcare providers toward HIV-positive female clients. Kenya was identified as a possible pilot site for numerous reasons. First, the KAIS revealed that more than half of HIV-positive women (57.9%) have an unmet need for family planning (NASCOP, 2009). Some sources attribute this gap to the inability of HIV-positive women to access FP and RH services as a result of healthcare provider attitudes (Center for Reproductive Rights and FIDA, 2008). Very little was being done to address this gap in the training of healthcare providers, especially among FP providers. Second, the project had been working with the RH/HIV Integration Committee in Kenya on drafting a national integration strategy. To develop this strategy, the project undertook a rapid assessment to identify policy and operational barriers to the integration of FP/RH and HIV services. The assessment revealed that some FP providers exhibited stigma and discrimination against HIV-positive women seeking services (Okundi et al., 2009).

In support of ongoing project efforts to design and implement a national RH/HIV integration strategy, in November 2008, the Health Policy Initiative met with the RH/HIV Integration Committee to introduce an activity on S&D and FP/RH services for HIV-positive women. The committee agreed on the importance of the issue, and the project and in-country stakeholders decided to create a training module on S&D for healthcare providers. In consultation with the committee, the team planned on designing a short training module that could be added on to existing training programs focusing on RH and/or HIV issues.

Methodology

To begin developing the module, the team reviewed existing S&D training resources on working with healthcare providers, including those focused on meeting HIV-positive women's RH needs. This review also included a global look at HIV-positive women's needs related to FP/RH, along with a specific focus on Kenya. In addition, the team reviewed current training curricula for Kenyan healthcare providers to assess existing content on S&D, particularly in relation to FP/RH service provision.

With this background, the team planned on collecting data on training needs. In partnership with the committee, the team selected a site for discussions with PLHIV support groups and a pre-training assessment with healthcare providers in the Central Province. The province was chosen because of its relatively low HIV prevalence in Kenya (possibly in part due to fewer people testing or reporting status) and thus limited number of HIV-related interventions. The team selected the Kirinyaga District for initiating the pre-training assessment with healthcare providers and for focus group discussions with PLHIV support group representatives on the FP/RH needs of HIV-positive women.

With the support of the MOPHS, DRH, and Provincial Director of Public Health and Sanitation in Central Province, the team contacted and undertook the pre-training assessment among service providers in three facilities in Kirinyaga District, as well as held discussions with PLHIV support groups of the Kerugoya District Hospital, Anglican Church of Kenya (ACK) Mt. Kenya Hospital, and Kimbimbi sub-district hospital. Based on suggestions from national PLHIV networks, the project also held discussions with the

PLHIV support group at Wamagana Health Center in Nyeri District. The assessment was completed in November–December, 2008.

Group discussions. The team conducted a group discussion with representatives of national PLHIV networks and organizations who were attending a project workshop in Nakuru, Kenya, in November 2008 (see Annex A for the questions). The discussion involved 30 PLHIV from a range of PLHIV networks and civil society groups serving HIV-positive people, including the National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK), Kenya Network of HIV-positive Teachers, Assalam Women Forum (AMWOF), Kenya Treatment Access Movement (KETAM), Kenya AIDS Network of Post-Primary Institutions, and United Disabled Persons of Kenya (UDPK). This discussion was initiated to understand the extent of stigma and discrimination PLHIV face while accessing FP/RH services, especially since these participants, as members of national groups, were presumed to be more aware of their rights.

The team also held four focus group discussions with representatives of local PLHIV support groups affiliated with the aforementioned health facilities. Approximately 50 participants (both women and men) took part in the discussions. One project team member led the discussions in Kiswahili and another took notes. The questions were designed to explore the participants' knowledge of reproductive health issues, including family planning, and their experiences in accessing local RH services (see Annex B).

Pre-training assessment. The project implemented the pre-training assessment in three sites—Kerugoya District Hospital, ACK Mt. Kenya Hospital, and Kimbimbi sub-district hospital—with a total of 19 healthcare providers. The team distributed a confidential, self-administered, anonymous questionnaire to various providers in FP clinics (2 providers), maternal and child health (MCH) clinics (4 providers), and comprehensive care centers (CCC) (13 providers). Respondents included one or more of the following: nurses, voluntary counseling and testing (VCT) counselors, social workers, health record officers, data clerks, pharmacy assistants, and laboratory workers. The questionnaire was designed to gauge the providers' work environment, knowledge, and attitudes (see Annex C).

Findings

National PLHIV Networks

The PLHIV participating in the discussion indicated a moderate level of awareness of the types of FP services available for HIV-positive people. Participants mentioned a wide variety of services or types of family planning, including condoms, the "morning after pill," traditional methods such as withdrawal (although there was some debate on the topic when a participant brought up re-infection), oral sex, and abstinence. For those who do want to have children, participants discussed the need for sperm washing for discordant couples and sperm donations for HIV-positive women. Participants were able to name some RH services for PLHIV, such as prevention of mother-to-child transmission (PMTCT), vasectomy, tubal ligation, and hysterectomy.

When asked if networks are working to reduce stigma and discrimination for PLHIV accessing RH services, most of the networks reported that they are doing so or that they knew of other networks that were doing so. For example, NEPHAK reported that JSK- African Medical and Research Foundation (AMREF) is targeting health workers to reduce stigma and discrimination, which includes FP and RH workers, in regional health facilities in the Meru, Central, Northeastern, and Nyanza provinces. It is also partnering with the AIDS, Population, and Health Integrated Assistance Project II (Coast and Rift) to assess all rights related to discrimination. Participants also reported that Alliance International had conducted a training on stigma reduction in a training-of-trainers (for 10 organizations) in Meru Hospital. KETAM reported working with health workers on stigma reduction in response to client complaints. It also applied the Stigma Index to assess stigma and discrimination in health facilities, which was an

activity supported by the Health Policy Initiative (Kamau, et al., 2007). Members of the Kenya Network of Religious Leaders Living with or Affected by HIV/AIDS reported working with a clinic in Mombasa and giving health talks that address S&D to patients in hospitals and dispensaries. AMWOF reported working with patients in Mombasa clinics on S&D through training and sensitizing them (including through support groups).

The team also asked questions in small groups to facilitate smaller discussions. In the group that was asked about receiving FP services, only one person out of six said that they had received FP services. When the entire group was asked this question, only three (two women and one man) said they had received services to help plan their families. One woman reported receiving RH services at Kenyatta National Hospital's obstetrics and gynecology clinic.

When asked if HIV-positive women experience S&D while seeking FP/RH services, based on their knowledge, most participants said "yes." They reported negative and demeaning language and body language from healthcare providers. One reported hearing something similar to "disabled, the virus, the pregnancy—which one will you be able to handle?" They also reported that stigma is higher for older women than for younger women due to assumptions that older women should have stopped having sex.

Participants were asked where HIV-positive women are more likely to experience stigma when accessing FP services—at FP sites, MCH sites, or CCCs? They responded that stigma is greatest at FP and MCH sites, as CCC providers are more sensitive and aware of the issues. Similarly, participants were asked the same question in reference to RH services, asking specifically about labor wards, maternity wards, PMTCT services, and gynecological wards. Responses varied, with reports of high levels of stigma in ANC clinics and minor theaters, gynecological wards, maternity wards, and labor wards. Some reported that in maternity wards, if there is a problem, caregivers and providers may leave women to bleed rather than stitch the woman up. PMTCT sites were seen as places with the least amount of stigma, as participants felt those providers have already been trained on the issues.

When asked which healthcare workers they thought the activity should train to reduce stigma related to providing FP/RH services to HIV-positive women, participants responded in the following order: maternity ward staff, FP providers, and CCC staff. Participants were also asked what they thought healthcare providers should learn or be trained on. Their responses included the following:

- The need to define stigma for providers (participants believed that providers would say they already know what it is)
- Their roles as health workers, specifically in relation to HIV-positive clients
- The effects of S&D on HIV-positive women
- How to develop a strategy for reducing S&D, such as improving communication skills for healthcare workers when interacting with HIV-positive women
- The need to create a positive or favorable environment for HIV-positive women seeking FP/RH services (participants mentioned that providers should be able to approach women and speak with them in a confidential setting, rather than in a queue with other people around)

Last, participants were asked if there was anything else to share regarding this topic. Participants emphasized the importance of discussing how culture affects HIV-positive women, including effects from religion and culture on family planning for HIV-positive women. They also spoke of the need for education on basic HIV information. UDPK also mentioned that FP/RH information and services for persons with disabilities is limited. In particular, condoms and literature are not accessible to the blind and most facilities are not physically accessible.

At the end of this session, it was clear that participants wanted more information on FP/RH for PLHIV; in evaluating the overall workshop, most participants asked for a future session or training on FP/RH for PLHIV.

PLHIV Support Groups

Many participants from the PLHIV support group discussions reported receiving no information on FP/RH issues. Discussions revealed that HIV-positive women understand family planning but often believe condoms are the only effective method for them, due to information from healthcare providers. Some women believe family planning reduces the strength and effectiveness of ART.

PLHIV reported that stigma is enacted through hurtful language and behavior (see Box 2). Participants said that providers often cite HIV as an explanation for any other health concerns they may have (i.e., once a client is HIV positive, the provider believes that all ailments revolve around his/her HIV status—which clients referred to as an "HIV coat").

Members of the Wamagana PLHIV support group in Nyeri District, Kenya. December 2008.

PLHIV reported that the highest level of stigma is experienced by pregnant women in maternity wards, including at the time of delivery. They said that the FP/MCH clinics have the second highest level of stigma, followed by the CCCs.

Box 2. How is Stigma Expressed?

Providers' hurtful words and judgmental attitudes
"Disability, the virus and pregnant, which one will you be able to handle?" —United Disabled Persons of Kenya Member

Being talked to like they should not be having sex

Being used as reference points during health talks; status made public

Other health concerns dismissed by providers
"These are your HIV issues!" —PLHIV support group member

Responses also showed that healthcare providers often supply misleading and harmful information about mother-to-child transmission of HIV, telling women they must have CD4 counts of 500 or above to safely bear children and that their risk of having an HIV-positive child is 50 percent. In addition, some providers advise against childbirth, saying that it will reduce their immunity. Furthermore, PLHIV reported that HIV-positive pregnant women often stop attending HIV clinics for care once they become pregnant because they do not want their provider to know they became pregnant. The pregnant women then go to general clinics for ANC where their status is not known, compromising their care. Participants reported that HIV-positive women are also advised to register for PMTCT programs when still in their first trimester, deliver through caesarean or normal delivery, and not to breastfeed after childbirth (formula feeding is recommended).

PLHIV also report that they are used as reference points during health talks, with their status being made public by healthcare providers to illustrate their points. Also, they experience judgmental attitudes, such as providers talking to them like they should not be having sex at all when seeking treatment for STIs.

Participants also noted that older women experience more stigma than younger women. On a positive note, pap smears were reported to be conducted free for PLHIV periodically.

Healthcare Providers

Training and education

Overall, the majority of the healthcare providers surveyed (16 of 19) reported receiving no training on FP/RH services for HIV-positive clients. One respondent noted that there is no training offered on counseling HIV-positive women on family planning and all methods of contraception. The majority of respondents had received training on providing HIV services (12 of 18), most likely because most of the respondents work in CCCs. They also reported limited training on RH and FP in general, which, in many cases, is outdated. Some providers had received FP/RH training 5–10 years ago. Respondents indicated a need and desire for more training on a range of issues, including family planning for HIV-positive women, ART, adherence, psychosocial aspects, and integration of counseling and testing in FP services.

ACK Mt. Kenya clinic in Kirinyaga District, Kenya. December 2008.

Attitudes and beliefs

When asked questions related to their attitudes and beliefs toward HIV-positive clients, most of the providers said they do not see HIV as a threat in their occupations. The majority (12 of 17) believed it is easy for clients to express their feelings and desires about sexuality with them. The majority also agreed that HIV-positive women can use most types of modern contraception (only one person disagreed). Few believed that giving too much information about sexuality and reproduction to HIV-positive women will make them promiscuous, but a few believed that HIV-positive people are responsible for getting infected (e.g., sex workers). More than half believe women face greater stigma than men (10 of 17). One respondent noted that it is difficult to reach men and bring them in for testing. Three of the 19 providers blamed positive HIV status on a lack of behavior change. However, all providers agree that HIV-positive clients have a right to be counseled on FP/RH issues.

Practices

All the providers who responded to the question (18 of 18) said that they provide the same care to HIV-positive clients as other clients. Providers believe that PLHIV have the right to access family planning and 15 of 17 said that they are comfortable providing counseling on family planning to clients who are HIV positive. Six out of 17 providers said that they do not counsel HIV-positive clients on modern contraceptives. In addition, three providers reported hearing other providers counseling HIV-positive clients against having children.

Provider concerns

Providers identified other issues they were concerned about, adding them to the bottom of the questionnaires. For example, some cited a shortage of staff; no adequate space for their work; lack of universal precautions, supplies, and other resources; and a need for trainings. Respondents specified training on cervical screening and other RH issues.

Creation of a Taskforce

After ensuring support from the national RH/HIV Integration Committee to develop a training module on S&D in relation to the RH needs of HIV-positive women, NASCOP and DRH, supported by the Health Policy Initiative, held a dissemination workshop to ensure wider buy-in from other stakeholders and to present findings from the pre-training assessment on April 30, 2009. The workshop objectives were to

- Disseminate the findings of the stigma and discrimination assessment;
- Agree on key messages to be included in the S&D training module for service providers; and
- Nominate a taskforce to lead drafting of the S&D training module.

DRH and NASCOP representatives began the meeting, highlighting the importance of the issue and the activity. Dr. Kigen, then Head of the DRH, noted that integrating HIV with the wide range of RH services is still fundamental, as the percentage of unmet need for FP among HIV-positive women is high. He also noted that FP need for HIV-positive women also includes spacing births. NASCOP's Integration Coordinator, Margaret Gitau, discussed how HIV testing has been integrated into RH services, so those who seek FP services can also be counseled and tested for HIV in the same facility. In addition, FP/RH services are now being offered in the CCCs, and there is a concern regarding whether health workers can provide RH services without stigma and discrimination.

Health Policy Initiative staff presented on the pre-training assessment undertaken in Kirinyaga District. The presentation included an overview of the methodology and the results from service provider and PLHIV discussions (including provider advice to PLHIV). The presentation included a review of implications and the recommendation that a training module be drafted to increase knowledge and sensitize FP, RH, and MCH providers on reducing S&D while providing FP/RH services to HIV-positive women. A plenary discussion followed the presentation, in which participants had the opportunity to offer their feedback on the presentation and the topic. Some comments focused on the difficulty service providers have in discussing RH issues due to their cultural backgrounds (e.g., some cultures do not allow condoms). Also, some felt that service providers are not well equipped—many are being trained on the job and, therefore, a module on S&D is essential. They also pointed out that male involvement is essential. Participants agreed that the S&D module should be incorporated into existing trainings such as pre-service training. The point was also made that service providers are not necessarily as difficult to work with as perceived, and some of them are not aware that they are engaging in discriminatory behavior.

Participants undertook group work to assist in the development of the training module. They were asked to identify the following:

- Key thematic areas for the S&D training module
- Key specific S&D areas
- Key topics or messages for each area

The feedback is presented in Table 1.

Table 1. Stakeholder Feedback on the Proposed S&D Training Course for Healthcare Providers

Thematic Areas	Specific areas	Key Messages
• Definitions (including stigma and discrimination) • Policies • Systems and structures • Basic facts (such as prevalence, methods of transmission, prevention, FP/RH rights) • Myths and misconceptions • Sources of S&D • Reasons for S&D • Types of S&D • How to overcome S&D	• Explore beliefs and attitudes leading to S&D • Human rights approaches and responsibilities • How stigma manifests and how to overcome S&D • Pregnancy and HIV issues • PMTCT, FP/RH services • Provider and client attitudes • Communication skills • Counseling • Difference between stigma and discrimination • Legal implications • Referral mechanisms	• What is stigma and discrimination? • Types and manifestations of S&D • Indicators of S&D • Causes of S&D • Strategies for S&D reduction • Knowledge and communication gaps • Infrastructure gaps • Facts on RH related to HIV/STIs, safe motherhood, PMTCT, and family planning • Clients' RH rights and responsibilities • Provider needs • Communication skills, client-provider interaction • Unbiased service provision • Reference to policy documents on service delivery • Community linkages • Referral systems

After discussing the results of the small group work, the participants reached consensus on the following key issues to cover in the training module:

- Definition and effects of stigma and discrimination
- Attitudes
- Ethical considerations
- Basic facts related to RH and HIV
- Strategies for reducing stigma and discrimination

In addition, it was noted that the group who worked on the training module should refer to existing materials while developing the module and include references to these sources. Also, the S&D module would be expected to fit into other existing training materials.

Last, participants agreed that a taskforce would oversee the development of the S&D training module. Approximately 15 members were drawn from the RH/HIV Integration Committee and other partner organizations with S&D-related activities:

- NASCOP
- National AIDS Control Council
- JHPIEGO
- Family Health International
- NEPHAK
- Pathfinder
- Liverpool VCT
- Healthcare providers
- DRH
- EngenderHealth
- World Health Organization
- KETAM
- Health Policy Initiative (secretariat)
- Family Health Options Kenya
- AMREF

The taskforce membership was drawn from organizations with a wealth of knowledge that could inform development of the module.

Development of the Training Module

Once established, taskforce members met to determine the way forward. They agreed to hire a consultant to draft the training module, which would aim to increase knowledge and sensitize healthcare providers on how to reduce stigma and discrimination while providing FP/RH services to HIV-positive women. The consultant produced an initial draft for taskforce members to review. The consultant then revised the module based on their feedback and organized a pilot-test of the module in July 2009.

Pilot Training of the Module

On July 27–28, 2009, the activity team conducted a pilot training of the module to assess its usefulness and feasibility. The training was originally scheduled to be held in Baringo District, where participants could spend two days focusing on the training. However, the activity team learned that important participants from the DRH were going to be in Mombasa for another training at the same time. To ensure their participation, the workshop was moved to Mombasa and held before the DRH representatives' other event. Since DRH was a target audience for the training, it was crucial to have their participation and receive their feedback and support (see Annex D for a list of participants).

The workshop's 23 participants included numerous stakeholders, such as representatives from PLHIV networks and support groups, NASCOP and DRH, healthcare providers, medical training school tutors, and taskforce members. To build on the pre-training assessment in Kirinyaga District, representatives also included two healthcare providers, a provincial trainer, and a representative of one PLHIV support group that took part in the earlier assessment.

On the first day, the facilitator—the consultant who designed the training module—conducted the training to pilot-test the module. He began with asking participants to define stigma and discrimination in their own words, followed by sharing their own experiences with S&D—not necessarily HIV related. The training components were as follows:

- Reproductive health and HIV
- Thoughts, beliefs, and attitudes relating to HIV and AIDS
- Stigma and discrimination as related to HIV
- Facets of stigma and discrimination and their effects
- Clients' rights and health workers' needs

After completing the pilot-test, participants offered feedback on the module design and made suggestions for revisions. The feedback was positive, and numerous suggestions for additional activities and components were suggested. For example, some participants felt that issues of sexuality should be included more prominently, that participants should identify S&D reduction strategies, and that role plays would be beneficial.

Finalizing of the Training Module

Following the workshop, the consultant incorporated the feedback into the trainers' manual and drafted a participants' manual. On September 29, 2009, the taskforce discussed the revised trainers' manual and determined the next steps. Overall, the taskforce endorsed and expressed satisfaction with the module's content. The taskforce extended the training to two days to allow sufficient time for each activity. It also determined that the training should be a stand-alone module that can be added onto existing RH or HIV trainings. In addition, facilitators would be able to pull out specific activities to integrate into existing trainings as needed.

With this endorsement, the taskforce then presented the module for review and discussion with the larger RH/HIV Integration Committee on January 27, 2010. The committee made suggestions to improve the flow of the module, endorsed its use, and recommended launching it through an initial training of healthcare providers (see Annex E for the training agenda). As of spring 2010, the training module was under final review by the RH/HIV Integration Committee (Ministry of Public Health and Sanitation and Ministry of Medical Services, forthcoming).

III. CONCLUSION

While healthcare providers believe that HIV-positive women have a right to be counseled on FP/RH issues, HIV-positive women have an unmet need for family planning. Findings from this activity indicate that healthcare providers often share limited or incorrect FP/RH information with HIV-positive women. In many cases, this is the result of a lack of knowledge and training on the issue. In other cases, this is the result of stigma and discrimination.

PLHIV support group and healthcare providers from the Kerugoya District Hospital, Kirinyaga District, Kenya. December 2008.

The process initiated in this activity (see Box 3) demonstrates Kenya's commitment to taking measures to ensure HIV-positive women's access to FP/RH. The training module developed under the RH/HIV Integration Committee will help providers deliver services in a non-stigmatizing and non-discriminatory manner. Healthcare providers would also benefit from up-to-date, periodic training on FP/RH issues and options for HIV-positive women. Such training would increase their knowledge on the types of family planning appropriate for HIV-positive women, which would also benefit PLHIV, who have expressed a desire to learn more about FP/RH.

Box 3. Summary of Key Steps in the Process

- Assessing existing resources related to S&D and HIV-positive women's needs for FP/RH
- Conducting interviews with FP providers and focus groups with members of support groups and networks of PLHIV, including both women and men, to discuss their S&D experiences in the context of accessing FP information and services
- Sharing the findings with the RH/HIV Integration Committee and later with a wider group of stakeholders
- Establishing a taskforce to guide the process of training module development, pre-test, and finalization
- Adapting existing training curricula on S&D into a module that includes family planning for a training-of-trainers for FP providers
- Pre-testing and revising the training module

Provider training on stigma and discrimination and training on technical and medical matters are particularly important in Kenya, where great strides have been made in support of RH/HIV integration. As the government continues to expand the integration of services, it will be increasingly important to ensure that healthcare providers have the information and training they need to provide high-quality FP/RH services to HIV-positive women. The initiative of the committee's Stigma and Discrimination Taskforce has shown that organizations and the government can work together for a specific purpose. The RH/HIV Integration Committee is currently doing a final review of the training module. Crucial to rolling out the training module will be further support of the Ministry of Public Health and Sanitation and Ministry of Medical Services to integrate the module with existing training programs.

ANNEX A: DISCUSSION QUESTIONS FOR PLHIV NETWORKS

Consultation: Discussion Questions with PLHIV Networks to develop the module
1–2 hours depending on discussion

1. Introductions (names and network, etc.)
2. Explanation of the S&D activity and the importance of collaboration with the PLHIV network

1. What family planning services are available for PLHIV?

2. What about reproductive health services for PLHIV?

3. How many of you have received services for family planning to help plan your family?
    a. If so, where did you receive your services?

4. And what about reproductive health services: Have you received them? And if so, where did you receive them?

5. Is there any network having activities that seek to reduce stigma and discrimination for people living with HIV accessing reproductive health services?
    a. If yes, what specifically are you doing?
    b. And with whom are you working?

6. Based on your knowledge, do positive women experience any stigma or discrimination when trying to obtain family planning or reproductive health services?
    a. If so, what types of stigma or discrimination do positive women experience?
    b. Is there any difference if the woman is young or older?

7. Where do positive women tend to experience the most stigma when accessing family planning services? FP sites, MCH clinics, or CCCs?

8. Where do positive women tend to experience the most stigma when accessing reproductive health services? During labor/labor wards; maternity wards; PMTCT; gynecological wards?

9. If we are to train healthcare workers on reducing stigma related to providing family planning and reproductive health services to positive women, who do you think needs the training most?
    a. Family planning providers? Or (b) people working in CCCs? (c) people working in labor/maternity wards?

10. What do you think those healthcare providers should learn/should be trained on to reduce stigma when providing FP and/or RH services to HIV-positive women?

11. Is there anything else you think we should know or hear from you to help us develop a training module or materials to reduce stigma related to giving family planning services to HIV-positive women?

We want to continue collaborating with the networks. Would any of you be willing to help review the outline of the training module?

ANNEX B: DISCUSSION QUESTIONS WITH LOCAL PLHIV SUPPORT GROUPS

Consultation: Discussion Questions with Local PLHIV Groups to Develop the Module

1–2 hours depending on discussion

- Introductions (names and network, etc.)
- Explanation of the Health Policy Initiative, the S&D activity, and the importance of collaboration with the PLHIV support groups

1. What family planning services are available for PLHIV?

2. What about reproductive health services for PLHIV?

3. How many of you have used family planning?
    a. If so, where did you receive your services?

4. And what about reproductive health services: Have you received them? And if so, which ones were/are they? And where did you receive them?

5. We are interested in hearing about all the services HIV-positive women receive. Do healthcare providers advise HIV-positive women on their reproductive health options?

6. Do you know if healthcare providers ever advise HIV-positive women against having children?

7. Do you know of HIV-positive women who have been forced by a healthcare provider to end a pregnancy? Use a specific method of giving birth? Feed their infants in a certain way?

8. Are HIV-positive women given information about healthy pregnancies and safe motherhood as part of a program to prevent transmitting HIV to their babies?

9. What are some of the problems and challenges for HIV-positive women when they visit health facilities to seek any type of RH services?

10. If we are to train healthcare workers on how to provide family planning and reproductive health services to positive women, who do you think needs the training most?
    a. Family planning providers? Or (b) people working in CCCs? (c) Any other?

11. What do you think those healthcare providers should learn about how to provide FP and/or RH services to HIV-positive women? Or what should they learn about the provision of FP/RH services to HIV-positive women?

12. Is there anything else you think we should know or hear from you to help us work with healthcare providers to improve family planning services for HIV-positive women?

We want to continue working with the support group/network to improve FP and RH service provision to HIV-positive women. What do you see as your contribution in this process? Would any of you be willing to assist us in working with the healthcare providers?

ANNEX C: PRE-TRAINING ASSESSMENT

Pre-training Assessment
Kirinyaga Health Facilities

This is anonymous and confidential

Name of facility:	**Sector/level of care** *(please circle)*: • CCC • FP • MCH	**Occupation:**

Please check the box for "yes" or "no."

Question	**Yes**	**No**	**Comment**
1. I have received training on providing services related to *reproductive health.*	If yes, how long ago?		
2. I have received training on providing services related to *family planning.*	If yes, how long ago?		
3. I have received training on providing services related to *HIV.*	If yes, how long ago?		
4. I have received training on family planning and/or reproductive health services for HIV-positive people.	If yes, how long ago?		
5. My facility has a policy that supports HIV-positive clients' confidentiality.			
6. My facility has a policy that supports HIV-positive staff's confidentiality and their right to continue working.			
7. Clients are welcome to services regardless of age, class, color, ethnicity, or HIV status.			
8. All clients are treated competently, equally, fairly, and respectfully, regardless of age, class, ethnicity, or HIV status.			
9. Services are provided to clients known to be HIV positive without separating them from other clients.			

Question	Yes	No	Comment
10. Prior to invasive procedures, patients are not selectively tested for HIV without their consent.			
11. Healthcare staff do not wear gloves or masks inappropriately with people who are HIV positive or presumed to be.			
12. My facility avoids labels or signs in the service delivery area that would draw attention to clients with HIV.			
13. HIV-positive clients are the biggest threat to my safety at my place of work.			
14. I feel that I am at high risk of acquiring HIV from working at a public health facility.			
15. People living with HIV should be ashamed of themselves.			
16. I would feel ashamed if I was infected with HIV.			
17. I would feel ashamed if someone in my family was infected with HIV.			
18. People infected with HIV are responsible for getting infected.			
19. Staff must treat all clients with respect and in a welcoming manner whether they are known or believed to be HIV positive.			
20. Health workers have a professional obligation to remain objective and nonjudgemental with clients, whether they are HIV positive or HIV negative.			
21. Withholding health services from a client believed or known to be HIV positive is a violation of the client's human rights.			
22. HIV-positive women often face more HIV stigma and discrimination by partners, friends, and family members than HIV-positive men because they are more likely to get an HIV test.			
23. It is easy for clients to express their feelings and desires about sexuality with their healthcare providers.			

Question	Yes	No	Comment
24. It is important for every HIV-positive woman to be counseled about her sexual and reproductive health.			
25. HIV-positive women have the same reproductive rights as women not infected by HIV; for example, they have the right to access family planning.			
26. Giving too much information about sexuality and reproduction to HIV-positive women will make them promiscuous.			
27. An HIV-positive woman's desire to get pregnant is an obstacle to discussing family planning options.			
28. HIV-positive women can use most modern contraceptive methods.			
29. I provide the same care to HIV-positive clients as other clients.			
30. I counsel women I know to be HIV positive on all methods of contraception.			
31. I am comfortable providing counseling on FP to clients who are HIV positive.			
32. I have told or have heard a colleague tell a woman known to be HIV positive that she should not have children.			
33. I know or know others of my colleagues who feel uncomfortable providing counseling on FP to clients who are HIV positive.			
34. I believe I or my colleagues provide the same level of FP counseling to all clients.			

ASANTE SANA FOR AGREEING TO SHARE WITH US
AND FOR YOUR VALUABLE TIME!

ANNEX D: PILOT-TEST WORKSHOP PARTICIPANTS

No	Name	Organization[2]
1	Zaituni Ahmed	Ministry of Health/Coast Province
2	Annette Musumba	Kenya Network of HIV-positive Teachers
3	Amina Ali	Assalam Muslim Women Forum
4	David Nyaberi	Division of Reproductive Health
5	Nick Kimeu	Family Health Options Kenya
6	Dorothy Odhiambo	USAID | Health Policy Initiative, Task Order 1
7	Mary Muchira	Ministry of Health/Kirinyaga District
8	Agnes Nzioka	Pumwani School of Midwifery
9	Teresa Kimondo	Wamagana PLHIV Support Group
10	Ruth Mwai	Ministry of Health/Kirinyaga District
11	Lilian Sigei	Ministry of Health/Rift Valley Province
12	Joyce Nganga	Liverpool Voluntary Counseling and Testing
14	Mary Ndirangu	National AIDS and STI Control Program
15	Rebecca Mwengi	Kitui Kenya Medical Training College
16	Celestine Muye	Ministry of Health/Malindi District
17	Joel Rakwar	Consultant
18	Beatrice Okundi	USAID | Health Policy Initiative, Task Order 1
19	Margaret Gitau	National AIDS and STI Control Program
20	Alice Njihia	Kenyatta National Hospital
21	Ruth Muia	Division of Reproductive Health
22	Gathari Ndirangu	Division of Reproductive Health/Capacity Project
23	Juweiriya Yunis	USAID | Health Policy Initiative, Task Order 1

[2] For ease of reference, the term "Ministry of Health" in this list is used to encompass the two health ministries, the Ministry of Public Health and Sanitation and the Ministry of Medical Services.

ANNEX E: TRAINING AGENDA

Day 1	Time
Workshop Overview - Welcome - Activity 1: Introduction and Norms - Activity 2: Pre-training Assessment - Activity 3: Workshop Objectives	9.00am–9.45am
Session 1: Introduction to Stigma and Discrimination - Activity 1: Defining Stigma and Discrimination - Activity 2: Experiences with Stigma and Discrimination	9.45am–10.45am
Tea Break	10.45am–11.15am
Session 2: Basic Facts about Reproductive Health and HIV - Activity 1: SRH Issues Relating to People Living with HIV - Activity 2: Informed Consent and Informed Choice	11.15am–12.15pm
Lunch	12.15pm–1.15pm
Session 2 (continued) - Activity 3: Client Rights and Healthcare Provider Needs - Activity 4: HIV Risk Continuum and Overview of Transmission - Activity 5: The Knowledge and Beliefs Gap - Activity 6: Family Planning Options for HIV-Positive Individuals	1.15pm–5.15pm

Day 2	Time
Session 3: Thoughts, Beliefs, and Attitudes Relating to HIV and AIDS - Activity 1: Values and Attitudes - Activity 2: Judging and Categorizing - Activity 3: Strategies for Counseling Clients on Sexual Matters	9.00am–10.30am
Tea Break	10.30am–11.00am
Session 4: Aspects of HIV-related Stigma and Discrimination and Their Effects - Activity 1: Stigma and Discrimination Relating to HIV and AIDS - Activity 2: Forms of HIV-related Stigma - Activity 3: Stigmatizing Language and Practices - Activity 4: Effects of Stigma and Discrimination	11.00am–12.30pm
Lunch	12.30pm–1.30pm
Session 4 (continued) - Activity 5: Discrimination Against Clients in Health Facilities - Activity 6: Summary of HIV and AIDS-related Stigma and Discrimination - Activity 7: Treating People in Non-Stigmatizing and Non-Discriminatory Ways	1.30pm–2.15pm
Session 5: Ethical Issues Relating to Stigma and Discrimination - Activity 1: Core Aspects of Ethics in Health Practice - Activity 2: HIV-related Case Studies and Individual Rights versus Public Health - Activity 4: Services for Most-at-Risk Populations	2.15pm–4.15pm
Session 6: Action Planning - Activity 1: Creating Action Plans - Activity 2: Post-Training Assessment and Closing	4.15pm–5.30pm

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