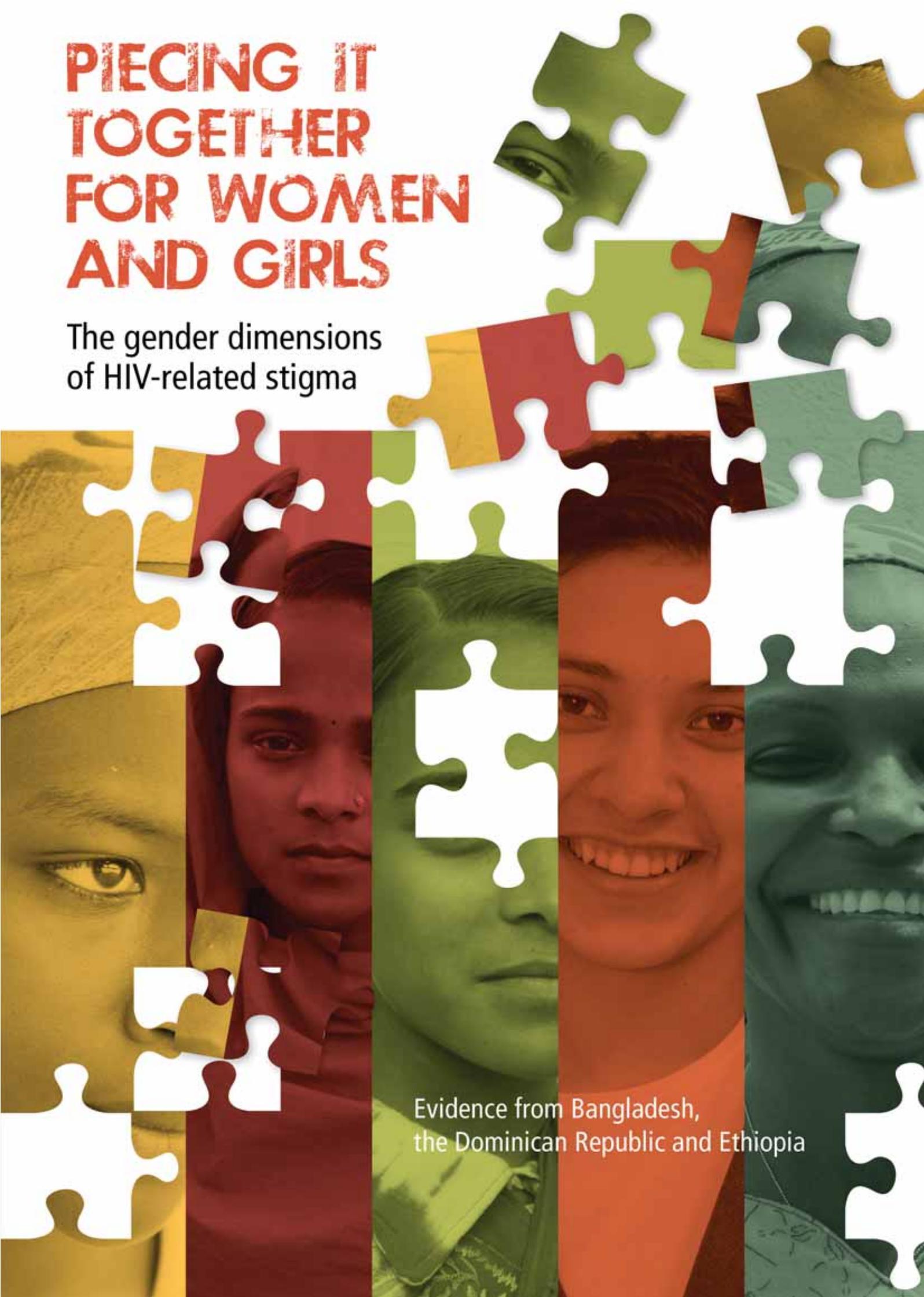


PIECING IT TOGETHER FOR WOMEN AND GIRLS

The gender dimensions
of HIV-related stigma

Evidence from Bangladesh,
the Dominican Republic and Ethiopia



DID YOU KNOW?

- >> Every day, more than 7,000 people become infected with HIV.
- >> Worldwide, over half of all people living with HIV are female.
- >> In sub-Saharan Africa, young women are up to three to four times more likely than young men to be HIV-positive.
- >> In Bangladesh, over half of women living with HIV have experienced stigma by a friend or neighbour; 87 per cent have decided not to get married as a result of their HIV status; and nearly a fifth feel suicidal.
- >> In Ethiopia, only 45 per cent of women living with HIV have disclosed their status to their partner or husband; over half have low self-esteem; and 44 per cent have been advised by a health worker not to have a child due to being HIV-positive.
- >> In the Dominican Republic, a fifth of women living with HIV have been coerced into being sterilized; 60 per cent fear being the subject of gossip; and nearly a quarter did not, while pregnant, receive ARV drugs for prevention of mother-to-child-transmission; 75 per cent of women give support to other people living with HIV.
- >> Action on HIV-related stigma and gender inequality are critical to achieving universal access to HIV prevention, care, support and treatment and the Millennium Development Goals.

FOREWORD

Piece by piece

HIV. Stigma. Gender. These three terms are all-too-frequently used together on any discussion related to the structural determinants or driving forces of the epidemic. Much time has been devoted to developing a deeper understanding of their connections at plenary addresses at AIDS conferences; articles in journals and all kinds of quantitative and qualitative research. Yet, despite all we have learned over the past three decades about HIV-related stigma, it continues to thrive – fuelling the continued expansion of the epidemic. It is imperative that we find innovative and personal ways to piece together the ever-growing rhetoric into tangible difference in the lives of people most affected by the epidemic. And in many countries around the world, these lives are those of key populations¹ and young women and girls.

Globally, women and girls make up more than half of all people living with HIV. This is particularly true in sub-Saharan Africa, which bears the brunt of the global HIV burden. The Caribbean is the only other region where the absolute number of women and girls living with HIV outnumbers men and boys. However, women account for a growing proportion of people living with HIV in Asia and Eastern Europe. It should therefore come as no surprise that the experience of HIV-related stigma today, particularly as it affects women and girls in these regions, will at times be very different to that of men and boys living with HIV. The reasons for and responses to this are illuminating. Addressing the gender dimensions of HIV-related stigma as it impacts on the lives of young women and girls requires a better understanding of where, when and how stigma affects them. By examining key settings, such as the workplace, health-care institutions, the family or the household, we may gain some insight about where the experience of stigma for women and girls is significantly different. Women-led solutions to proactively address stigma may indicate how empowered women and girls are and whether the policy environment protects and guarantees their rights.

Piecing together the various parts of a response to HIV-related stigma – to match the realities of the lives of different women and girls – requires that policy makers and programme experts; advocates and activists; researchers and academics work towards a collective goal. Responses must be carefully crafted and become ‘fit for purpose’ to effectively address the most pressing bottlenecks. These strategies could include:

Fit for research and policy: Policy development should be informed by a fully disaggregated analysis of the situation, where the differences are explored by gender (not just by sex), and the research agenda and policy process should work in tandem with the life experiences of women living with HIV.

Fit for advocacy: Young women and girls are not passive victims of HIV-related stigma, but the impact of HIV-positive women’s activism and advocacy needs to be better understood and taken to scale. Indicators that measure stigma need to be tailored to the realities of women’s lives.

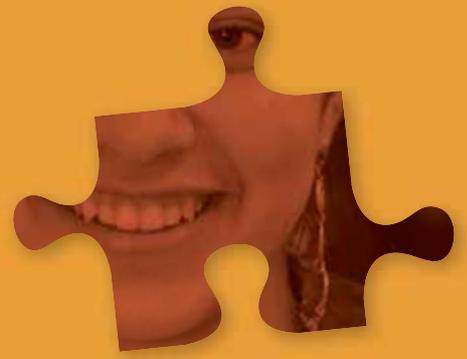
Fit for learning: Openly HIV-positive women staff – in health service settings especially – has a significant impact in creating or enhancing an atmosphere of respect, support and solidarity for HIV-positive women.

Responses to stigma must evolve and develop in line with the nature of HIV-related stigma, which is ever-shifting and changing. We hope that this document will provide some insight on piecing together the various elements to address the nuances of HIV-related stigma as it affects young women and girls.

¹ ‘Key populations’ refers to groups of people who are both more vulnerable to and affected by HIV. In most contexts, these include men who have sex with men, people who use drugs and sex workers and their clients.

Acronyms

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARVs	Antiretroviral drugs
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
GCWA	Global Coalition on Women and AIDS
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater involvement of people living with HIV
GIZ	Deutsche Gesellschaft fuer Internationale Zusammenarbeit
GNP+	Global Network of People Living with HIV
HIV	Human immunodeficiency virus
ICASO	International Council of AIDS Service Organizations
ICW	International Community of Women Living with HIV
IPPF	International Planned Parenthood Federation
MDG	Millennium Development Goal
NGO	Non-governmental organization
PMTCT	Prevention of mother-to-child transmission (of HIV)
SRHR	Sexual and reproductive health and rights
Stigma Index	People Living with HIV Stigma Index
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
WHO	World Health Organization



CONTENTS

Introduction: What is this report?	4
Context: Why does this matter?	5
HIV-related stigma: A persistent reality	5
HIV-related stigma and gender: An inextricable link?	5
Framework: Levels of gender dimensions of HIV-related stigma	7
1. Health	7
2. Work	8
3. Social	8
4. Rights	9
Country case studies: What are the gender dimensions of HIV-related stigma?	11
Bangladesh	12
Dominican Republic	17
Ethiopia	22
Analysis: What does this mean?	27
Resources: What's out there?	30
Call to action: What needs to happen?	32

INTRODUCTION

What is this report?

This report focuses on the gender dimensions² of HIV-related stigma. It aims to fill a gap and advance a more nuanced understanding and more effective advocacy on how stigma affects women and girls living with HIV more, less or differently to men and boys.

This is an advocacy tool for use by relevant stakeholders – from international donors to global policy makers, national governments, programme managers, civil society and people living with HIV. It builds on current policy debates by providing concrete evidence from three diverse countries (Bangladesh, Dominican Republic and Ethiopia) that have implemented the People Living with HIV Stigma Index (see Figure 1).

The report starts by outlining the context: explaining the pieces of the HIV, gender and stigma 'jigsaw' and providing a framework for analysis. (This framework is based on four, interwoven levels where the gender dimensions of HIV-related stigma are most prevalent: health, work, social settings and rights.) It then uses that framework to present case studies from the three countries – using quantitative and qualitative information to illustrate what the gender dimensions of HIV-related stigma mean in reality. It then draws conclusions about key commonalities, differences and issues across the countries.

The report ends with a Call to Action to mobilize all relevant stakeholders to play their full role in responding to the gender dimensions of HIV-related stigma.

Figure 1: The People Living with HIV Stigma Index

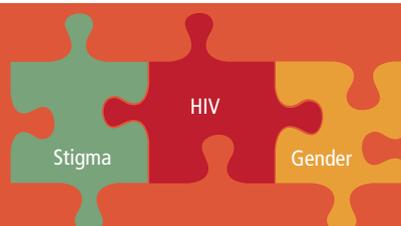
The Stigma Index was developed by and for people living with HIV to measure and build evidence about the stigma experienced by people living with HIV in their communities. It is an innovative research tool that translates every day, anecdotal evidence into systematic and measurable data that can be used to track changes, support advocacy and inform policies and programmes.

The Stigma Index is based on responses from a survey that covers ten key areas: experiences of stigma and discrimination and their causes; access to work and services; internal stigma; rights, laws and policies; effecting change; HIV testing; disclosure and confidentiality; treatment; having children; and problems and challenges.

To date, the Stigma Index has been rolled out in over 20 countries. The process is as important as the product: the Stigma Index puts the greater involvement of people living with HIV and AIDS (GIPA) principle into practice, being driven by people living with HIV and their networks and providing them with an opportunity to address challenges in their communities and catalyse change.

The Stigma Index was developed and pioneered by a partnership between the International Planned Parenthood Federation (IPPF) and the Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV (ICW) and Joint United Nations Programme on HIV/AIDS (UNAIDS). For more information, please visit www.stigmaindex.org.

Figure 2: The 'jigsaw' of HIV, gender and stigma



² This report focuses on the dynamics and differences between women and men. However, it is acknowledged that the term 'gender' more broadly refers to the full range of issues relating to women/girls and men/boys, including sexual minorities.

CONTEXT

Why does this matter?

HIV-related stigma: A persistent reality

Worldwide, stigma and discrimination are characteristic of diverse contexts and countries. It is often based on perceptions of, and negative responses to, 'differences' between individuals, families and communities. For example, on the grounds of age, race or social status.

During the course of the global epidemic, HIV-related stigma has been a particularly pernicious and persistent reality.

Stigma against those who are known or presumed to be living with HIV remains a fundamental barrier to the achievement of key mandates set by governments around the world. These include universal access to HIV prevention, care, support and treatment³ and the Millennium Development Goals⁴.

Stigma related to HIV is fuelled by a broad range of factors, from fear of transmission to associations with 'taboo' subjects, such as sex, sexual orientation and drug use. The impact of stigma can be immense. It can be felt at many different levels – from the mental and physical well-being of an individual to the ability of health systems to reach those most in need and of governments to lead effective, rights-based responses.

Stigma and discrimination can be obvious, for example when a person living with HIV is refused a health service. But it can also be more subtle, for example when a person is not fully included in group activities. Individuals, organizations, institutions or systems can stigmatize or discriminate, or both, against people based on HIV status. People living with HIV can also stigmatize themselves – 'self stigma'. For example, someone living with HIV may choose to exclude themselves from a social event because they feel or perceive that they will not be welcome.

HIV-related issues may be just one of many, interwoven types and layers of the 'stigma jigsaw' that a person experiences. For example, those from key populations – such as sex workers and people that use drugs – often also experience stigma related to their status or behaviour.

HIV-related stigma and gender: An inextricable link?

Worldwide, there are significant, often entrenched, inequalities related to gender. These are driven by a broad range of factors that manifest themselves at multiple settings within the lives of women, girls, men and boys. Examples of these settings include: economic (with women having unequal opportunities to earn income, lacking control over resources, etc); social (with women and girls experiencing violence, lacking decision-making power within sexual relations, etc); and political (with women lacking protection of inheritance rights under the law, having their choices about their sexual and reproductive health and rights (SRHR) limited by restrictive policies, etc).

These existing gender-based inequalities are compounded and, in turn, exacerbated by HIV. As a result, women and girls living with HIV often experience an interwoven and over-lapping jigsaw of stigma – due to their HIV status and being female. The situation is further exacerbated for key populations.

³ *Political Declaration on HIV/AIDS*, United Nations General Assembly, June 2006.

⁴ *United Nations Millennium Declaration*, United Nations General Assembly, 2000.

Figure 4: Perspectives on HIV-related stigma by partners of the Global Coalition on Women and AIDS



“ Stigma stands in the way of women realizing their rights. So how can progress be made in overcoming this? How can we change people’s attitudes to AIDS? A certain amount can be achieved through the legal process, or through institutional and other monitoring mechanisms which can enforce the rights of women living with HIV and provide powerful means of mitigating the worst effects of discrimination and stigma. For example, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) is a critical tool for assisting all of us to understand what gender equality and the elimination of discrimination will require. It is a powerful mandate for bringing about concrete changes to realize women’s human rights ... However, no policy or law alone can combat HIV-related discrimination. A more enabling environment needs to be created and fear-based messages and biased social attitudes need to be confronted in order to reduce the discrimination and stigma of women living with HIV. This can only be done by supporting the leadership of HIV-positive women and their groups to increase their visibility and capacity to challenge stigma. They need to know their rights and be empowered to claim them.”

*Nazneen Damji, Programme Manager: Gender Equality and HIV/AIDS,
United Nations Entity for Gender Equality and the Empowerment of Women*

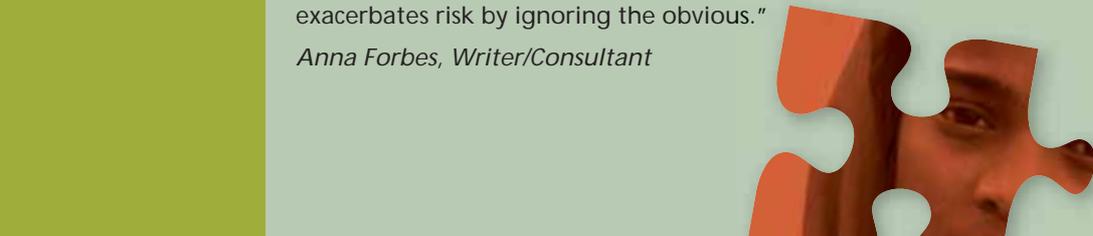


“ Whether as wives or mothers, as women who use drugs or as women who sell sex ... women and girls, because of gender inequality and stereotypes, experience profound stigma. For example, women experience greater stigma than heterosexual men for selling sex – as it goes against ideas of women upholding societal virtues and needing to belong to one man. As a result, female sex workers are more likely to experience housing discrimination, violence, discrimination against their children and other forms of stigma. Across the board, we see stigma made worse by gender prejudices and the idea that a woman’s biology sets her destiny. We will never make progress in the response to HIV – prevention, treatment, care or support – unless we deal with the gender dimensions of HIV-related fear and ill-treatment.”

Robert Carr, Director of Policy and Advocacy, International Council of AIDS Service Organizations

“ Fueled by unfounded hate, fear, and ignorance, stigma manifests in too many heinous forms. Stigma thrives because we let it. Despite the feeble justifications, it is unconscionable to tolerate, let alone practise it. There is simply no place for stigma; never was, never will be. Why wait? Play your part now, help human rights prevail.”

Lynn Collins, Technical Advisor for HIV, United Nations Population Fund



“ Working together to analyze the relationship between gender, stigma and HIV is an inescapable commitment for ICW Global, these three elements were the issues that led to the creation of the network in 1992. This document provides valuable input into a discussion enriched by our visions on stigma, gender and HIV, so that they offer new tools to face the challenges of current times and the immediate future in a better way. This has always been a goal of women living with HIV at ICW Global.”

Patricia Perez, Chair of the International Community of Women Living with HIV (ICW) Global

“ HIV/AIDS shines a bright spotlight in the fault lines of stigma in our societies. Since stigma and marginalization fuel HIV transmission, increasing HIV rates trace an undeniable map showing where stigma is the strongest – against homosexuality, illicit drug use, selling sex, and against women simply for being women. Women who are beaten for suggesting condom use, sex workers who struggle for safety on the streets, uneducated girls who are chattel on the marriage market, widows who lose their property and autonomy – all suffer HIV risk that is generated by sexist stigma. Talking about HIV prevention without talking about stigma reduction and human rights is a hollow effort to paper over these gaping fault lines in our social structures. As this report shows, it wastes money and exacerbates risk by ignoring the obvious.”

Anna Forbes, Writer/Consultant

Framework: Levels of gender dimensions of HIV-related stigma

In the past three decades, women and girls living with HIV have often been at the forefront of ground-breaking action. They have demonstrated immense courage – speaking out against inequality, confronting gender-based violence and seeking sexual and reproductive health services – despite multiple and significant barriers. They have shown that stigma can be challenged and can be overcome.

However, despite such efforts, for many women and girls, the gender dimensions of HIV-related stigma remain a reality. And there is little nuanced understanding of how and why the jigsaw of that reality varies between individuals, communities and contexts.

This report uses four settings to provide a framework for analysis. The settings – 1. Health, 2. Work, 3. Social, 4. Rights – were selected as areas in the lives of women and girls living with HIV where stigma is reported to be most prevalent and significant.⁵



1. Health

HIV-related stigma can be a major barrier to the access of women living with HIV to services not only for HIV, but other areas of health. This is particularly seen in the continuum of services needed throughout a woman's life. Within mainstream services – such as government antenatal programmes – women living with HIV may face stigmatizing attitudes and inappropriate actions by both staff and other clients, for example that they do not have the 'right' to enjoy sexual relations or have children.⁶ In addition, gender inequality affects practical issues, such as a woman's access to money, mobility and, in turn, choice of services.

In particular, HIV-related stigma can influence a woman's decisions about her reproductive choices and prevention of mother-to-child transmission (PMTCT).⁷ Even where available, women may not access relevant services – for fear of revealing their HIV status and experiencing the consequences (for example, abandonment by partners and family). Each component of PMTCT – from receiving home visits to taking antiretroviral therapy (ART) – risks revealing the woman's status in the health facility, her community and/or family. Similarly, a woman using formula feed for an infant risks isolation within societies where breastfeeding⁸ is the norm.⁹

Stigma can particularly affect a woman's use of life-saving ART – in terms of whether they attend the health facility in the first place and/or whether they comply with their regimen for treatment. This can be due to a number of factors, such as women's fear of being seen at an 'HIV centre' or lacking private places at home to store the drugs.

Access to services – and the influence of stigma – can be especially challenging for women living with HIV who are from key populations.¹⁰ For example, accessing ART may require a female sex worker to reveal both her HIV status and her work – risking multiple layers of stigma.

⁵ Note: Unless otherwise stated, the following analysis is based on the findings of the People Living with HIV Stigma Index in Bangladesh 2008, the Dominican Republic 2008 and Ethiopia 2010 – as described in the subsequent case studies.

⁶ Diaz, N. V., Rivera, S. M. & Cintron, F (2008) AIDS Stigma Combination in a Sample of Puerto Rican Health Professional: Qualitative and Quantitative Evidence. *Puerto Rico Health Sciences Journal*, 27 (2), pp. 147-157; and Thomas, B., Nyamathi, A. & Swaminathan, S (2009) Impact of HIV/AIDS on Mothers in Southern India: A Qualitative Study. *Aids and Behavior*, 13 (5), pp. 989-996.

⁷ ICRW and London School of Hygiene and Tropical Medicine (2010) *Modelling the Impact of Stigma on HIV and AIDS Programmes: Preliminary Projections for Mother-to-Child Transmission*. London: ICRW and London School of Hygiene and Tropical Medicine.

⁸ ICRW and London School of Hygiene and Tropical Medicine (2010) *Modelling the Impact of Stigma on HIV and AIDS Programmes: Preliminary Projections for Mother-to-Child Transmission*. London: ICRW and London School of Hygiene and Tropical Medicine.

⁹ Sibeko, L., Coutsooudis, A., Nzuzi, S. & Gray-Donald, K. (2009) Mothers' Infant Feeding Experiences: Constraints and Supports for Optimal Feeding in an HIV-Impacted Urban Community in South Africa. *Public Health Nutrition*, 12 (11), pp. 1983-1990.

¹⁰ UNAIDS (2005) *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*. Geneva: UNAIDS.



2. Work

Gender dimensions can exacerbate experiences of HIV-related stigma and further de-stabilize the livelihoods of women. More women than men work in the informal sector (where work lies outside of any formal regulatory environment)¹¹ and their often marginal work might be jeopardized by discrimination from the community. For example, they may choose to buy fruit from different vendors because of their HIV status. In more formal employment settings, women may be more vulnerable to discriminatory practices by employers, fellow employees and clients. It may be necessary for a woman living with HIV to take considerable time to attend hospital and other appointments, particularly when travelling from rural areas. This can mean a loss in income or poor attendance record. As a result, women living with HIV may decide not to attend the clinic for fear of being penalized or 'found out' at work.

Many women living with HIV are able to lead full and active working lives, but may take decisions to change or reduce their employment due to HIV. For example, they may prefer to work in the informal sector – to avoid having to disclose their status within a more formal environment.

However, there may also be times when a woman living with HIV cannot work – for example, due to her own ill health or caring for other family members – which leads to a loss of income without any opportunity to substitute that loss. The result can mean hardship and poverty. Issues of self-esteem and internalized stigma can also affect decisions about employment, such as dissuading an HIV-positive woman from applying for a job or a promotion.

Many women living with HIV are also fully able to engage in education, but, again, may face significant barriers – for example due to discriminatory attitudes by teaching staff.



3. Social

HIV-related stigma in social settings can impact on a woman's and girl's ability to participate in family and community life, maintain her mental health, adhere to medication, maintain her reproductive health, safely feed infants and enjoy her sexuality and rights. Women whose daily lives often centre on the household and community may be more likely to be seen accessing HIV services or to face social pressure to be open about health issues with their family, including in-laws.

Stigma can be particularly intense – even overwhelming – for women living with HIV from particular types of communities, such as those in rural areas, of ethnic minorities or that are strongly conservative or religious. Here, women can experience multiple layers of the 'jigsaw' of stigma and discrimination. They may be forced into 'protective silence' which means that they do not seek support from the community or services, including in terms of accessing ART and other medication. Meanwhile, in all communities, women's experiences of HIV-related stigma vary depending on other factors in their life, such as their marital status and age.

HIV-positive women and girls often fear stigma and rejection by their close family members and loss of shelter, status and stability (such as inheritance rights and access to children). Such stigma may be overt (with a family treating a woman living with HIV less favourably than her HIV-positive husband) or more subtle (with a woman's role in food preparation gradually reduced). The family environment can be particularly challenging for non-breastfeeding mothers living with HIV – who can face pressure, gossip and questions about their unconventional choices.¹²

¹¹ ILO/SEAPAT's OnLine Gender Learning & Information Module, available at: www.ilo.org/public/english/region/asro/mdtmanila/training/unit2/asiainfm.htm

¹² *Modelling the Impact of Stigma on HIV and AIDS Programmes: Preliminary Projections for Mother-to-Child Transmission*, ICRW and London School of Hygiene and Tropical Medicine, 2010.

Within intimate relationships, HIV-related stigma can be influenced by gender patterns. Women are often the first to know their status, for example if they are tested when going for antenatal screening, and can then be blamed for bringing ill health into a relationship.¹³ This can be particularly so when the other partner's status is unknown or undisclosed, and processes of denial associated with coming to terms with an HIV-positive diagnosis can also lead to accusations of infidelity. Women may particularly fear the repercussions of HIV-related stigma by their partners, such as physical violence and verbal abuse.¹⁴ They may also find it particularly difficult to negotiate sexual relations – with gender stereotypes making it 'unacceptable' for women to speak openly about safer sex and condom use.¹⁵



4. Rights

Even in contexts where national legislation, such as anti-discrimination laws, has been introduced to address HIV-related stigma, issues of gender often remain neglected. Some well-intended national policies risk actually exacerbating the gender dimensions of stigma. National policies that assume disclosure of HIV-positive status to a sexual partner is 'risk free' and a moral responsibility ignoring the very real concerns of women and girls who fear violence or rejection from partners or family as a result of disclosure. Routine testing of women in an antenatal settings without counselling mean that women are often aware of their status before their partners, placing them at heightened risk of accusations of infidelity and violence. Women who learn their status in this manner are also at heightened risk of emotional trauma and depression when they receive results for which they have not been prepared, often made worse by concerns for their child and fear of perinatal transmission.

Some women's groups have turned to law-makers to protect women and advocated for criminal prosecutions to be used in response to HIV transmission. However in most cases, although further research is needed, the legislation seems to have, to the contrary, *targeted* women.¹⁶ It is evident that criminalizing transmission means criminalizing the behaviour of people living with HIV, thus stigmatizing and discriminating against all individuals living with HIV. Women and girls are disproportionately affected by the discriminatory criminalization laws since they are more likely to be tested for HIV and, therefore, know their status – either through routine gynaecological examinations or pre-natal care. This can potentially lead to disproportionate prosecution of women for the transmission of HIV.¹⁷

In addition, statutory or customary laws often overtly discriminate against women, such as laws that deprive them of equal property rights.

Finally, policies in sectors as diverse as education, labour, housing and agriculture can reinforce gender discrimination and HIV-related stigma, as can laws (or the lack of them) on issues such as rape, abortion, drug use, sex work and inheritance. Meanwhile, protocols relating to areas such as health service management, medical training, partner notification and health insurance are also fundamental to the degree of stigma that is experienced by women living with HIV.

¹³ *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*, UNAIDS, 2005.

¹⁴ *Non-Discrimination in HIV Responses*, Paper to 26th Meeting of UNAIDS Programme Coordinating Board, UN AIDS, 2010. Also, for more information about the results from the People Living with HIV Stigma Index in the Dominican Republic – with a focus on gender-based violence – see: www.profamilia.org.do/Imagenes/uploads/files/Documentos/Publicaciones/Estigma%20y%20discriminacion%20VIH%20final.pdf

¹⁵ *Non-Discrimination in HIV Responses*, Paper to 26th Meeting of UNAIDS Programme Coordinating Board, UN AIDS, 2010.

¹⁶ *Verdict on a Virus: Public Health, Human Rights and Criminal Law*, IPPF, 2009.

¹⁷ *10 Reasons Why the Criminalisation of HIV Exposure or Transmission Harms Women*, ATHENA Network, AIDS Legal Network and AIDS and Rights Alliance for Southern Africa, 2009.

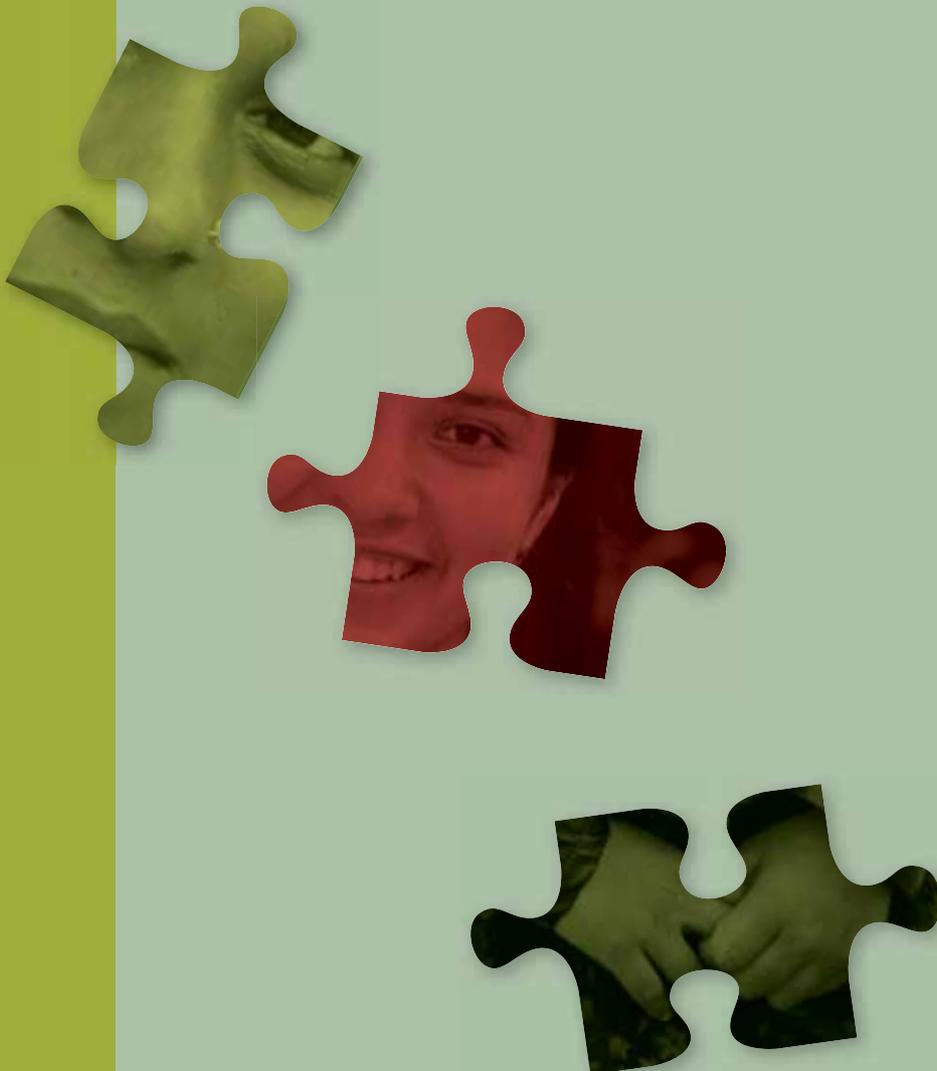
Figure 5: The jigsaw of the gender dimensions of HIV-related stigma – an experience from Bangladesh

The following quote, from a participant in a group discussion in Bangladesh, shows how the four levels of HIV-related stigma – health, work, social and rights – can combine and inter-relate within the life of a woman living with HIV:

“ My husband was abroad for a long time before we got married. I heard he tested positive at that time and was sent back to the country, but he married me without revealing any of this. He became sick two months after our marriage and went to India for treatment. After he was sent back, I saw his medical report and realized that I could have become infected too. I started to become sick quite often. My in-laws would then scorn my health condition and ask my husband, ‘What kind of a wife have you brought home? She is always sick!’ I became very worried after testing positive. I cried all the time and did not talk to anyone. I always thought about my child and worried about what would happen after I died. This feeling cannot be described in words.

I am divorced and have left my in-laws’ house. My husband used to torture me, and the children in that neighbourhood would not play with my child. My husband had gone around telling our previous neighbours about my positive status. They started making comments about me. Once my child had become critically ill and, when we went to the hospital, I informed the doctor that my child and I were both positive. I wanted the doctor to take precautions against becoming infected themselves. I hoped that my child would receive better service because I had already revealed our status, but the opposite ended up happening. The services became worse. They would not come near my child and wore gloves while treating my child. I had to explain to them that this was not a contagious condition.

I also face economic problems. I have been deprived of any property rights because I am HIV-positive. I got nothing from my husband or in-laws. I need to take money from my brothers. But, even in spite of having the money, medicine is sometimes still not available. Some medicines are very costly.”



COUNTRY CASE STUDIES

What are the gender dimensions of HIV-related stigma?

The following pages provide case studies to illustrate what the gender dimensions of HIV-related stigma mean in reality. They are taken from three countries with diverse cultures, contexts and HIV epidemics – Bangladesh, the Dominican Republic and Ethiopia – that have implemented the Stigma Index.

The case studies specifically focus on evidence of how HIV-related stigma affects women and girls more, less or differently than men and boys, rather than presenting the overall findings from the Stigma Index in each country.¹⁸ All of the information is taken from the results and reports of the Stigma Index process. The quantitative data from the survey is complemented by quotes from qualitative focus group discussions and interviews carried out with people living with HIV.

Each case study is divided into the following sections:

Context: Giving a snapshot of the overall national profile of how HIV affects women and girls

Research: Describing the process to implement the Stigma Index

Evidence: Summarizing the key information about gender dimensions of HIV-related stigma for: 1. Health, 2. Work, 3. Social, 4. Rights

¹⁸ Further details about the Stigma Index in each country are available at: www.stigmaindex.org or by directly contacting the in-country implementing partners.

BANGLADESH

Context: What is the profile of the country?¹⁹

Overall profile	
Population	164 million
Life expectancy at birth	67 years
Population living below poverty line	36%
Unemployment rate	5%
Women and girls profile	
Female literacy rate	76%
Average age at first marriage (female)	19 years
Modern contraceptive prevalence	48%
Maternal mortality ratio	570 maternal death per 100,000 live births
HIV profile	
HIV prevalence (general)	0.1%
HIV prevalence (15-25 years)	0.1% (female) and 0.1% (male)
Number of women living with HIV	1,900
% of people living with HIV needing ART that receive it	23%
% of HIV-positive pregnant women receiving ART for PMTCT	n/a
Examples of populations most affected by HIV	Migrant workers, people who use drugs, and sex workers
Law/regulations protecting people living with HIV against discrimination	No
Key gender-related drivers of the HIV epidemic	Low socio-economic position of women, high number of male overseas migrant workers, and patriarchal and conservative traditional culture

¹⁹ Data for population below poverty line and unemployment rate from *The World Factbook*, Central Intelligence Agency (accessed 7.2.11) www.cia.gov/library/publications/the-world-factbook/geos/et.html; other data for overall and women and girls profiles from: *State of the World Population 2010*, UNFPA, 2010; and data for HIV profile from *Global Report: UNAIDS Report on the Global AIDS Epidemic 2010*, UNAIDS, 2010.

Research: where and how was the Stigma Index carried out?²⁰

The Stigma Index was carried out from October to December 2008 as a collaboration between the Ashar Alo Society, Family Planning Association of Bangladesh, UNAIDS and the James P Grant School of Public Health, BRAC University. The survey involved 238 people living with HIV from ten divisions. It was translated into Bangla and implemented by a research team of anthropologists and people living with HIV. The profile of the 86 (36 per cent) female participants was:

- >> **Age:** 1% 18-19 years, 7% 20-24 years, 16% 25-29 years, 46% 30-39 years, 25% 40-49 years and 6% 50+ years
- >> **Location:** 8% rural area, 65% small town or village and 27% large town or city
- >> **Duration living with HIV:** 19% 0-1 years, 56% 1-4 years, 23% 5-9 years, 1% 10-14 years and 1% 15+ years
- >> **Children:** 91% at least one child and 15% a child living with HIV
- >> **Relationship status:** 66% married or cohabitating (partner in household), 3% married or cohabitating (partner away), 4% in a relationship, but not living together, 7% single, 6% divorced/separated and 14% widow
- >> **Key population:** 3% sex worker, 1% person that uses drugs, 2% internally displaced person and 2% migrant worker
- >> **Highest level of education:** 23% no formal education, 28% primary school, 38% secondary school and 11% technical college/university
- >> **Employment status:** 20% full-time employment, 4% part-time employment, 20% full-time self-employment, 21% part-time self-employment/casual work and 35% unemployed/not working

Also, 30 interviews were carried out with individuals recommended by the research team or from under-represented populations (including sex workers, migrant workers, people with children living with HIV, people who use drugs and *hijra* (transgender people)). These were conducted in the local language and in 14 districts. Among the participants, 15 were females, 14 male and one *hijra*, and about half were married.

In November and December 2010, the Stigma Index was followed-up by six focus group discussions (involving 60 women who had participated in the Stigma Index from six areas) and 18 in-depth interviews (targeting men) to explore selected issues. These were organized by the Ashar Alo Society and led by researchers from the Stigma Index.

Evidence: What were the key findings of the Stigma Index related to gender?



1. Health

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Access to health services: Very few women had been denied family planning or SRHR services due to being HIV-positive. However, the majority of women (67 per cent) had not told their health care worker that they were HIV-positive and many hid their status in order to access health services. Many only sought services in extreme situations – as they feared stigma by health workers. Among reports of being ignored or mistreated in hospitals, examples were cited of nurses breaching confidentiality and wearing gloves for clients living with HIV. Such measures drove women away from medical services and towards traditional or religious healers.

“ The doctor asked me after my test, ‘What have you done that has caused you this disease?’ ”
Woman living with HIV, Bangladesh

“ I think sexual activity is the main reason for my disease. I don’t feel interested in sex anymore. ”
Woman living with HIV, Bangladesh

²⁰ Information in case study referenced from: *People Living with HIV Stigma Index Study in Bangladesh* (draft), James P Grant School of Public Health, BRAC University, 2009; *Bangladesh Stigma Index: Qualitative Data Assessment Among the Stigma Index Interviewees*, Ashar Alo Society, December 2010; and *PLHIV Stigma Index Draft Results: Bangladesh*, 17th June 2010.

HIV testing: Most women (56 per cent) had had an HIV test due to their partner testing HIV-positive. This contrasted with men, of whom the largest proportion (39 per cent) had been tested in relation to employment, followed by 25 per cent in relation to having HIV-related symptoms. Only about half of women (49 per cent) took their own decision to have a test. However, this was considerably higher than for males, of whom only a quarter were not coerced into having a test, while 46 per cent had been tested without their consent (often within medical checks for migrant work). Meanwhile, only about half of women had received both pre- and post-test counselling. But, again, this was significantly higher than for men, of whom only 11 per cent received both types and 43 per cent received no counselling at all within migration-related processes.

SRHR options: Almost all (94 per cent) of women living HIV had received counselling on reproduction since their diagnosis. However, over a quarter (27 per cent) had been advised by a health worker not to have a child. Meanwhile, 11 women reported that they had been coerced into an infant feeding practice, two into termination of pregnancy, two into a method of giving birth and one into sterilization.

PMTCT: Only 12 per cent of women stated they had received ART for PMTCT, while a large number (40 per cent) had been refused the treatment, 5 per cent did not know it existed and 2 per cent could not access it. This reflected the lack of routine inclusion of PMTCT in government services, in the context of a low prevalence epidemic.

Antiretroviral therapy: Under half of women surveyed (48 per cent) were taking ART, fewer than men (51 per cent).

Sexual relations: Some 72 per cent of women were sexually active - a lower proportion than for men (88 per cent). Many negatively associated sex with HIV and 37 per cent had decided not to have sex due to their status.



2. Work

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Employment: A lower percentage of women than men reported loss of job/ income or refusal of work due to being HIV-positive. However, the majority of women – and significantly more than men – were unemployed or not working (64 per cent compared to 19 per cent).

Socio-economic status: Women's low socio-economic status – such as with 28 per cent lacking any formal education – was exacerbated by negative cultural reactions to HIV.

For example, participants cited examples of having their property or money taken from them by HIV-negative family members or being written out of the wills of parents or spouses.



3. Social

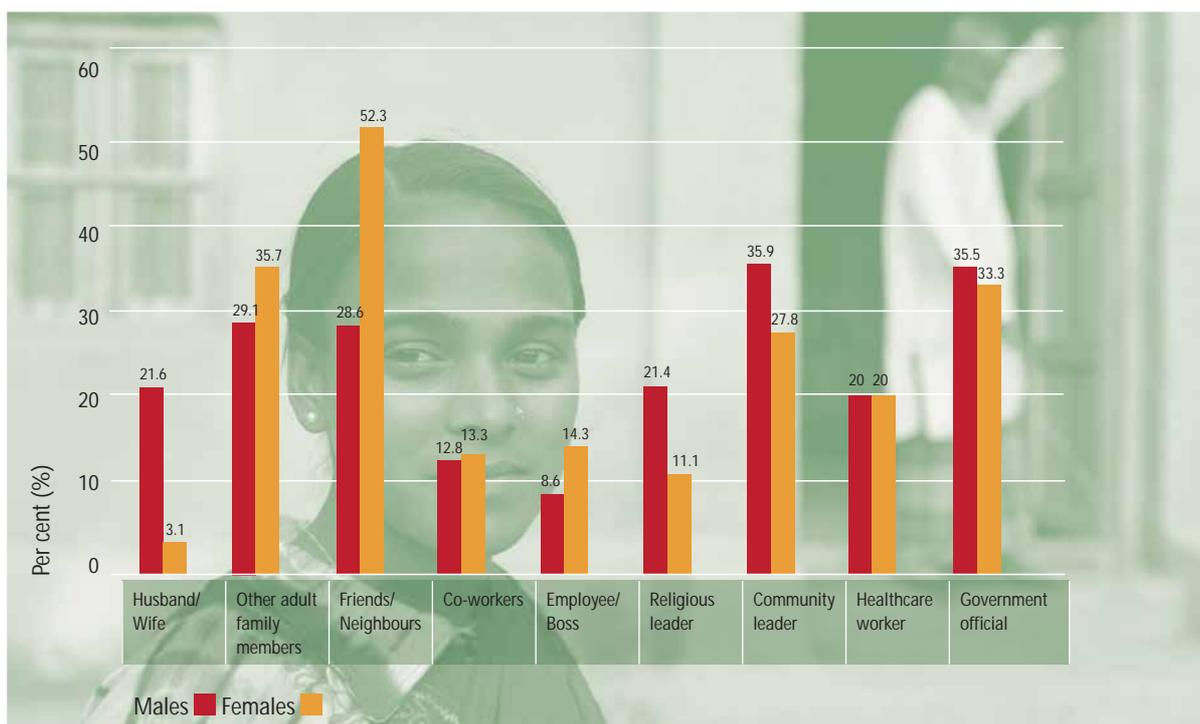
Evidence of the gender dimensions of HIV-related stigma included in relation to:

Internal stigma: Many women felt shame (60 per cent) and low self-esteem (38 per cent) due to being HIV-positive. But men showed even higher levels of those and all other indicators of self-stigma. Most men blamed themselves for their status (88 per cent compared to 20 per cent of women), while most women (70 per cent compared to just 6 per cent) blamed others. In the group discussions, almost all women felt that HIV was brought into relationships by men and some felt intense anger towards their husbands. They stated that HIV is perceived as only being spread through 'immoral' behaviour (such as extra-marital sex) and there are many misconceptions. Some women themselves believed the virus to be contagious and took extreme measures, such as isolating themselves in a room of their house or having separate bowls to the rest of their family.

Life choices: Due to their HIV status, many women had taken potentially negative decisions about their future. The vast majority (87 per cent) had decided both not to get married and not to have (more) children – higher levels than for men.

Exclusion and discrimination: While men living with HIV were more likely to have experienced discrimination by key local stakeholders (such as religious leaders, community leaders and government officials), women were much more likely to have been discriminated against by friends and community members (52 per cent compared to 29 per cent of men) (see Figure 6). The group discussions provided graphic illustrations of the impact of such experiences within highly conservative and religious communities. Instances were cited of women living with HIV: being thrown out of their in-laws' houses after disclosing their status; being rejected by their own family; having their property and money taken from them; facing pressure to become pregnant; not being allowed to touch people or objects; being verbally abused for being too ill to perform daily chores; and being treated as a 'sinner'. Many issues particularly affected widows, as well as women who were divorced, separated or living alone (who are looked down upon by society). Meanwhile, those identifying as sex workers or people that use drugs reported additional discrimination for belonging to minority groups that have very low social status.

Figure 6: Experiences of discrimination by men and women living with HIV, Bangladesh



“ I know it is sex, not blood that gave me this deadly virus. I really felt shamed for having a sexual disease.”

Woman living with HIV, Bangladesh

“ He killed my only child, my daughter. She was just three years old ... she died with AIDS. Her father gave her this shameful death ... Now tell me whom should I blame?”

Woman living with HIV, Bangladesh

“ All my clothes have been burnt. They [mother and father-in-law] did not allow me to talk to anyone. When I used to cut vegetables they asked me not to because I had a nasty disease.”

Woman living with HIV, Bangladesh

“ I know someone who lives in Gazipur ... Neighbours torture her. They don't allow her kids to play with anyone else's kids.”

Woman living with HIV, Bangladesh

“ I felt like killing myself and my two kids many times because, after having this disease, a lot of things started to happen to me which I never thought possible.”

Woman living with HIV, Bangladesh

Disclosure of HIV status: Less than half of women (44 per cent compared to 54 per cent of men) had chosen to tell their HIV status to their partner. But a further 24 per cent had had their status told to their partner by someone else without their consent. When disclosing, women were more likely to get a discriminatory/very discriminatory response from other adult family members and friends/neighbours. Also, only 58 per cent received a supportive/very supportive response from their partner. In the group discussions, many women described their strong reluctance to reveal their HIV status to their family or community. They also cited examples of men living with HIV marrying without disclosing their status.

Discrimination of children: A higher proportion of women had at least one child (91 per cent compared to 78 per cent of men) and a child living with HIV (15 per cent compared to 5 per cent). Many women shared strong and emotional concerns about the impact of stigma on their children, with incidents cited of inhumane treatment by others, including community members and health care professionals.

Other people living with HIV: About half of women (although a lower proportion than men) had provided emotional support to other people living with HIV. Also, lower levels had provided physical support or referral.



4. Rights

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Abuse of rights: In the survey, men and women reported similar and relatively low levels of abuse of their rights as a person living with HIV. However, in the group discussions, individuals shared many examples of abuse perpetrated by a range of stakeholders, including law enforcement officials. Some 7 per cent of men (compared to none of the women) had been forced to disclose their HIV status to enter another country. Women had taken low levels of action to redress incidents of abuse, although a slightly higher level than men (16 per cent versus 14 per cent) had personally confronted someone carrying out discrimination.

Support organizations: Women had very slightly higher knowledge of people living with HIV networks and NGOs, while men knew more about national NGOs and the National AIDS Council. All of the participants were a member of a network of people living with HIV, but women were less likely to be volunteering or working for a support project or to be involved in an organization addressing rights.

Achieving change: In terms of actions to address stigma, three-quarters of women (75 per cent) – a higher proportion than for men – recommended awareness raising with the public about HIV.

“ One of my uncles informed the police about my HIV status. The police took me away and kept me locked in a room.”

Woman living with HIV, Bangladesh

“ I did not get justice when the members of my husband’s family captured everything after the death of my husband. They told me that since I am HIV-positive, I should not have the need for any property.”

Woman living with HIV, Bangladesh

DOMINICAN REPUBLIC

Context: What is the profile of the country?²¹

Overall profile	
Population	10.2 million
Life expectancy at birth	73 years
Population living below poverty line	42%
Unemployment rate	14%
Women and girls profile	
Female literacy rate	97%
Average age at first marriage (female)	21 years
Modern contraceptive prevalence	70%
Maternal mortality ratio	150 maternal deaths per 100,000 live births
HIV profile	
HIV prevalence (general)	0.9%
HIV prevalence (15-25 years)	0.7% (female) and 0.3% (male)
Number of women living with HIV	32,000
% of people living with HIV needing ART that receive it	47%
% of HIV-positive pregnant women receiving ART for PMTCT	n/a
Examples of populations most affected by HIV	Men who have sex with men and sex workers
Law/regulations protecting people living with HIV against discrimination	Yes
Key gender-related drivers of the HIV epidemic	Low socio-economic position of women, early sexual debut, and multiple sexual partners

²¹ Data for population below poverty line and unemployment rate from *The World Factbook*, Central Intelligence Agency (accessed 7.2.11) www.cia.gov/library/publications/the-world-factbook/geos/et.html; other data for overall and women and girls profiles from: *State of the World Population 2010*, UNFPA, 2010; and data for HIV profile from Global Report: UNAIDS Report on the *Global AIDS Epidemic 2010*, UNAIDS, 2010.

Research: Where and how was the stigma index carried out?²²

The Stigma Index was carried out from May to July 2008, led by the Asociación Dominicana Pro Bienestar de la Familia and Instituto de Estudios de Población y Desarrollo, in collaboration with Red Dominicana de Personas que Viven con el VIH y SIDA and Alianza Solidaria para la Lucha contra el VIH/SIDA. The process used the Stigma Index survey, with additional questions on gender-based violence. It was implemented in all four main areas of the country (Santo Domingo, Cibao, Southeast and Southwest) and reached a total of 859 people living with HIV. The profile of the 429 (51 per cent) female participants was:

- >> **Age:** 3% 18-19 years, 9% 20-24 years, 18% 25-29 years, 37% 30-39 years, 22% 40-49 years and 10% 50+ years
- >> **Location:** 18% rural area, 31% small town or village and 47% large town or city
- >> **Duration living with HIV:** 15% 0-1 years, 39% 1-4 years, 29% 5-9 years, 10% 10-14 years and 6% 15+ years
- >> **Children:** 90% at least one child and 51% a child living with HIV
- >> **Relationship status:** 43% married or cohabitating (partner in household), 4% married or cohabitating (partner away), 7% in a relationship, but not living together, 15% single, 17% divorced/separated and 14% widow
- >> **Key population:** 8% sex workers, 2% people who uses drugs, 3% internally displaced people, 1% indigenous group and 89% migrant workers
- >> **Highest level of education:** 13% no formal education, 52% primary school, 29% secondary school and 6% technical college/university
- >> **Employment status:** 12% full-time employment, 14% part-time employment, 4% full-time self-employment, 10% part-time self-employment/casual work and 60% unemployed/not working

The survey was complemented by four focus group discussions involving 33 people living with HIV in four regions (National District, South Region, Eastern Region and Northern Region). The majority (63 per cent) were female and of an average age of 30 years. The largest proportion (32 per cent) had reached secondary level schooling, while 33 per cent had no formal education. While the largest number (30 per cent) was self-employed/ informal workers, 28 per cent were employed in the private sector and 28 per cent were unemployed/not working.

Evidence: What were the key findings of the Stigma Index related to gender?



1. Health

Evidence of the gender dimensions of HIV-related stigma included in relation to:

HIV testing: For women, the most common reason for having taken an HIV test was pregnancy (30 per cent), while for men it was having symptoms of HIV infection (29 per cent). Women were less likely to have taken a test under pressure or coercion from others, but also less likely to have received any pre- or post- test counselling.

SRHR options: Only 59 per cent of women had received reproductive counselling since being diagnosed with HIV, although the level was higher than for men (46 per cent).

In practice, such services had often had negative consequences, for example with more women than men reporting being advised not to have children (28 per cent versus 16 per cent) or coerced into sterilisation (20 per cent versus 3 per cent). Further analysis of the data indicates that women had different experiences according to their age. While older women were less likely to receive counselling about reproductive options, younger women were more likely to be encouraged or forced into negative decisions. For example, of the 101 women coerced into sterilisation, 52 were under 30 years old. Of particular concern,

²² Information in case study referenced from: *HIV and AIDS-related Stigma and Discrimination in the Dominican Republic*, Red Dominicana de Personas que viven con el VIH y SIDA, December 2010; *Stigma and Discrimination in People Living with HIV*, Asociación Dominicana Pro Bienestar de la Familia and Instituto de Estudios de Población y Desarrollo in collaboration with Red Dominicana de Personas que viven con el VIH y SIDA and Alianza Solidaria para la Lucha contra el VIH/SIDA; and *PLHIV Stigma Index Draft Results: Dominican Republic*, 17th June 2010.

four of them were aged just 18-19 years (representing over a quarter of the female participants in that age range). Such data was verified in the group discussion where women in the Southern Region spoke powerfully about being sterilized, often under moral pressure and without their consent.

PMTCT: Nearly a quarter (23 per cent) of women who had been pregnant during the past five years had not been given ART for PMTCT – due to lack of availability of, access to or knowledge of the drugs.

Sexual relations: Fewer female than male participants (63 per cent compared to 79 per cent) were sexually active. Over a quarter of women (28 per cent compared to 12 per cent of men) had taken a decision not to have sex due to their HIV status.

Antiretroviral therapy: A slightly lower number of women than men were taking ART (69 per cent compared to 72 per cent). The group discussions highlighted that women's self-esteem was affected by experiencing, or fear of experiencing, physical symptoms associated with treatment, such as the side effect lipodystrophy (fat redistribution) – which could affect body image and lead to stopping treatment.

- “ Because of being HIV-positive, I was sterilized ... They told me that it wasn't good for people living with HIV to have more children.”
Woman living with HIV, Dominican Republic
- “ No one asked me [about sterilisation]. They got me ready and told me afterwards.”
Woman living with HIV, Dominican Republic
- “ I have three daughters. One was born after I have this disease. When I was going to give birth, they didn't want to give me a caesarean.”
Woman living with HIV, Dominican Republic
- “ My wife decided not to have children because of fear ... when she was pregnant, she was afraid when we lie in bed and we think about what it would be like, how will the baby be? Will it be infected? Or will it not be? And for this reason she decided not to have more children. I would have liked to give my daughter a little brother.”
Man living with HIV, Dominican Republic



2. Work

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Employment: Women living with HIV were twice as likely as men to be unemployed or not working (60 per cent compared to 27 per cent). Almost all of the women (89 per cent) identified as migrant workers, while 8 per cent identified as sex workers.



3. Social

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Internal stigma: For women, being HIV-positive was more likely to be associated with self-stigma (see Figure 7). Higher percentages than men felt ashamed (41 per cent versus 23 per cent) and had low self-esteem (38 per cent versus 27 per cent). However, women were much less likely to blame themselves for their HIV status (29 per cent compared to 41 per cent of men). Nearly half of all women, and twice as many as men, blamed others.

Life choices: For all 10 indicators assessed, women were more likely than men to have taken potentially negative decisions about their life as a result of self-stigma relating to HIV. Of particular note, 27 per cent had decided not to attend a social gathering (compared to 18 per cent of men), 29 per cent not to get married (compared to 19 per cent) and 67 per cent not to have more children (compared to 51 per cent).

“ [Stigma is] when you get treated differently ... making you feel rejected or when your rights are denied.”

Woman living with HIV, Dominican Republic

“ Regularly, when I went to the salon to fix my nails, I felt rejected and got depressed. I heard the neighbours saying ‘Oh she is strange. She appears to have HIV!’ So my self-esteem was through the floor.”

Woman living with HIV, Dominican Republic

Exclusion and discrimination: Male and female people living with HIV reported similar and quite low levels of social exclusion, such as from family events. However, two thirds of women (higher than for men) were aware of being gossiped about. Overall, women appeared to be more fearful of discrimination, for example with 60 per cent (compared to 48 per cent of men) fearing being the subject of gossip. This was confirmed in the group discussions where women cited incidents of being talked about, especially by community members. Women were also more likely to fear being physically harassed and insulted. The exception was rejection from sexual intimacy – which was feared by slightly more men than women (34 per cent compared to 31 per cent).

Disclosure of HIV status: Women were more likely to have disclosed their HIV status to those closest to them, including their partner and children. The exception was friends and neighbours – who women were less likely to have told, but more likely to have had their status revealed by others without their consent. Generally, men and women received similar types of responses to disclosure, but women more often got a discriminatory/very discriminatory response from their partner (29 per cent versus 19 per cent).

Discrimination of children: Almost all women (90 per cent) had at least one child, while over half (51 per cent) had a child living with HIV. Both levels were higher than for men (67 per cent and 37 per cent respectively). The group discussions highlighted that women were particularly concerned about the impact of their HIV status on their children, for example in terms of them experiencing discrimination in educational settings.

Gender-based violence: The extra questions added to the survey identified high levels of violence experienced by women living with HIV. Almost a third (31 per cent) had been verbally or physically humiliated by their partner and 24 per cent had been threatened with physical harm to themselves or someone close to them. Over half (53 per cent) had been the subject of some type of battering since the age of 15.

Housing: Women living with HIV were more likely to have experienced difficulties relating to accommodation (23 per cent compared to 17 per cent of men) and to associate those difficulties with their HIV status.

Other people living with HIV: While less likely to provide other people living with HIV with material assistance, women were more likely to provide emotional support. They were also more likely to provide people with referrals (21 per cent compared to 13 per cent of men).

Figure 7: Experiences of self-stigma among women living with HIV, Dominican Republic

Indicator of self-stigma	Females	Males
I feel ashamed	41%	23%
I have low self-esteem	38%	27%
I feel I should be punished	6%	6%
I feel suicidal	10%	6%
I blame others	49%	22%
I feel guilty	27%	33%
I blame myself	29%	41%



4. Rights

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Abuse of rights: Over a quarter of women – and a higher percentage than men (26 per cent compared to 23 per cent) – had had their rights as a person living with HIV abused. Just 8 per cent of those women had sought legal redress. On the other hand, women were generally more likely to have taken more personal action – with 37 per cent having confronted or educated someone who was stigmatizing them (compared to 31 per cent of men).

Support organizations: Women had greater knowledge than men about different types of organizations providing support in relation to stigma. For example, 64 per cent knew of a support group for people living with HIV (compared to 59 per cent of men) and 15 per cent knew of the National AIDS Council (compared to 10 per cent). Low numbers of both women and men (11 per cent and 7 per cent) had actually sought help from such groups.

Policy commitments: More women than men (48 per cent versus 43 per cent) knew of the Declaration of Commitment on HIV. A similar pattern (73 per cent versus 65 per cent) was seen for knowledge of Law 55-93 (the National AIDS Law in the Dominican Republic).

Achieving change: A larger number of women were involved in a project or programme providing assistance to people living with HIV (26 per cent compared to 18 per cent of men). Yet fewer women than men felt that they had the power to influence local, national or international projects, policies, treaties or legal matters affecting people living with HIV.

ETHIOPIA

Context: what is the profile of the country?²³

Overall profile	
Population	85 million
Life expectancy at birth	56 years
Population living below poverty line	39%
Unemployment rate	n/a
Women and girls profile	
Female literacy rate	39%
Average age at first marriage (female)	16 years ²⁴
Modern contraceptive prevalence	14%
Maternal mortality ratio	673 maternal deaths per 100,000 live births ²⁵
HIV profile	
HIV prevalence (general)	2.4% (2.8% female and 1.8% male) ²⁶
HIV prevalence (15-25 years)	3.5%
Number of women living with HIV	717,669
% of people living with HIV needing ART that receive it	61.8%
% of HIV-positive pregnant women receiving ART for PMTCT	10%
Examples of populations most affected by HIV	Sex workers, long distance truck drivers
Law/regulations protecting people living with HIV against discrimination	No
Key gender-related drivers of the HIV epidemic	Low socio-economic position of women, high number of male overseas migrant workers, and patriarchal and conservative traditional culture

²³ Data for population below poverty line and unemployment rate from *The World Factbook*, Central Intelligence Agency (accessed 7.2.11) www.cia.gov/library/publications/the-world-factbook/geos/et.html; other data for overall and women and girls profiles from: *State of the World Population 2010*, UNFPA, 2010; and data for HIV profile from information cited in *Gender and Stigma in the HIV/AIDS Spectrum: Results from the Ethiopian Stigma Index Survey*, first draft, Tsegazeab Bezabih and Zena Berhanu, December 2010.

²⁴ DHS 2005 www.measuredhs.com/pubs/pdf/FR179/FR179.pdf

²⁵ DHS 2005 www.measuredhs.com/pubs/pdf/FR179/FR179.pdf

²⁶ MOH/HAPCO, 2007, Single point prevalence estimates

Research: Where and how was the Stigma Index carried out?

The Stigma Index was carried out from June to August 2010, led by the Network of Networks of HIV Positives Ethiopia (an umbrella organization of groups of people living with HIV) and Tsegazeab Consultancy. It used a survey translated into four local languages to gather nationally representative quantitative data from 3,353 people living with HIV in two City Administrative Councils and all nine Regional States. It was implemented by a team of 116 interviewers and 22 field supervisors. The participants were selected in collaboration with local stakeholders, such as health facilities and support groups for people living with HIV. The profile of the 2,280 (68 per cent) female participants was:

- >> **Age:** 15% 18-19 years, 8% 20-24 years, 27% 25-29 years, 44% 30-39 years, 15% 40-49 years and 5% 50+years
- >> **Location:** 28% rural area and 72% urban area
- >> **Duration living with HIV:** 18% 0-1 years, 56% 1-4 years, 24% 5-9 years, 2% 10-14 years and 1% 15+years
- >> **Children:** 80% at least one child and 29% a child living with HIV
- >> **Relationship status:** 33% married or cohabitating (partner in household), 4% married or cohabitating (partner away), 4% in a relationship, but not living together, 16% single, 17% divorced/separated and 27% widow
- >> **Key population:** 3% sex worker, 1% refugee/asylum seeker, 2% internally displaced person and 10% migrant worker
- >> **Highest level of education:** 43% no formal education, 37% primary school, 18% secondary school and 2% technical college/university
- >> **Employment status:** 11% full-time employment, 9% part-time employment, 31% full-time self-employment, 24% part-time self-employment/casual work and 25% unemployed/not working

The survey was complemented by 30 focus group discussions (15 women and 15 men) to collect qualitative information. These were carried out in 15 towns across seven regions and two city administrations. They involved 240 people living with HIV, mostly from urban areas, and focused on the participants' experiences, perceptions, contexts, consequences and responses related to stigma.

Evidence: What were the key findings of the Stigma Index related to gender?



1. Health

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Access to health services: Both men and women living with HIV reported low levels of denial of general health, family planning or SRHR services. However, the group discussions showed that denial can particularly affect women who are pregnant or delivering a child. Experiences were shared about lack of cooperation by health workers and preferential treatment for HIV negative clients. In at least one instance, such discrimination had had fatal consequences (see Figure 11 in the Analysis section).

HIV testing: Women were most likely to have had an HIV test due to pregnancy or the illness/death of a partner/family member. The majority had taken the decision to have a test by themselves (81 per cent), but a higher proportion than men (17 per cent versus 13 per cent) had taken the decision under pressure from others.

SRHR options: Only 62 per cent of women living with HIV had received counselling about reproductive options since being diagnosed. Yet a large proportion (44 per cent) had been advised by a health worker not to have children, while 14 per cent had been told that access to ART was conditional on using certain types of contraception and 7 per cent had been coerced into infant feeding practices. Also, 4 per cent reported being coerced into being sterilized and 2 per cent into terminating a pregnancy.

PMTCT: Some 18 per cent of women had received ART for PMTCT. But, despite the expansion of PMTCT services, a further 18 per cent of women who knew their HIV status while pregnant did not know of such treatment, 4 per cent could not access it and 1 per cent were refused it. Among those receiving PMTCT, nearly 15 per cent did not get information about healthy pregnancy and motherhood. In the discussions, some women, especially in religious areas, had been tempted to breastfeed to avoid the stigma of formula feeding.

Sexual relations: Fewer women living with HIV were sexually active (39 per cent compared to 61 per cent of men). Almost half of women had decided not to have sex due to their HIV status.

Antiretroviral therapy: With a free government programme, a large number of people living with HIV were taking ART, although slightly fewer women than men (88 per cent compared to 92 per cent). Among those not currently taking ART, fewer women than men said they could access the drugs when they needed them.



2. Work

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Employment: Within formal employment, women were slightly less likely than men to be affected by issues such as loss of job. However, most women (55 per cent) were in self or informal employment. Here, without formal procedures, they were particularly vulnerable to stigma. For example, women selling traditional beer faced clients' fears of it being infected with HIV, while some women entered sex work or traditionally male jobs in order to survive.

Socio-economic status: Women had higher unemployment than men and almost half (43 per cent) lacked formal education. Their households had much lower monthly incomes, with 95 per cent living below the poverty line. Also, women had more problems with credit for accommodation, particularly if widowed.

“ I have three children ... My husband has died. In order to raise them up, I am doing a man's job ... I am carrying stones at construction sites.”

Woman living with HIV, Ethiopia

“ Women who lost their husbands will not get collateral to get access to loan ... I cried loudly due to having nothing to feed my children.”

Woman living with HIV, Ethiopia

“ [A] house help had served the woman for 25 years. But the woman threw her out when she realized that she was HIV-positive.”

Woman living with HIV, Ethiopia

“ There are some HIV-positive women who are involved in commercial sex work by stating that they do not have anything to eat and drink.”

Woman living with HIV, Ethiopia



3. Social

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Internal stigma: Women living with HIV showed higher levels of many indicators of self-stigma, such as low self-esteem (54 per cent), shame (46 per cent) and suicidal feelings (22 per cent). But, while women were more likely to blame others for their status, men were more likely to blame themselves and feel guilty. The group discussions indicated that women sometimes had better coping strategies than men, such as being more likely to share their feelings with other women.

Life choices: HIV had led many women to reduce their aspirations and life goals, with 62 per cent deciding not to have (more) children and 44 per cent not to get married – both levels higher than for men.

Exclusion and discrimination: Men and women experienced similar levels of HIV-related stigma in social settings. However, women felt that they were more likely to be gossiped about – as confirmed in the group discussions, with many reports of being called ‘aidsome’ (possessor of AIDS). Also women were especially vulnerable to stigma in cultural events. Examples include: feasts (where they were denied their traditional role of food preparation); coffee ceremonies (where their cups were washed in boiled water); and funerals (where other mourners avoided touching them). Stigma could be especially intense for women in rural and Muslim communities where HIV is strongly associated with adultery.

Disclosure of HIV status: Over half of women had disclosed their HIV status to adult family members and children, but fewer had disclosed to others, such as friends. Generally, women received more negative reactions than men. Meanwhile, significantly fewer women had disclosed to their partner (45 per cent compared to 64 per cent). Of those, only about a third had received a supportive response. The group discussions showed that, where sero-discordance occurs, it is more likely to end in divorce if the woman is HIV-positive. In such cases, men are likely to reject their wives and elders to give him the property.

Discrimination of children: Women showed heightened concern about the impact of their own or their child’s HIV status on children in social and educational settings. In one instance, when the director of a kindergarten prohibited a mother from registering her HIV-positive child, the mother’s friends had advocated to the director about the child’s right to an education.

Gender-based violence: More women than men had been physically assaulted in relation to their HIV status and, among them, about a quarter had been assaulted by their husbands/partners.

Housing: Women living with HIV faced additional challenges securing accommodation. In the group discussions, participants spoke of women being accused of having more water consumption – an excuse to increase their rent or evict them. In Mekelle, a woman living with HIV was asked to pay 500 birr for a house previously rented for 200 birr. When she agreed, she was told the rent had gone up to 1,000 birr. The participants stated that such high costs could lead women to sex work in order to survive.

Other people living with HIV: Most women (58 per cent), although fewer than men, had provided support to other people living with HIV. Also, fewer women were involved in projects to support people living with HIV or efforts to change relevant legislation or policies (see Figure 8).

“ In our locality, there is stigma among husband and wife. Usually the husband gets tested somewhere without informing the wife. Even when he becomes positive he takes the medication outside. She doesn’t know and he didn’t give advice for her.”

Woman living with HIV, Ethiopia

“ When the husband died [the family] forced the woman to leave the house with her two children within a year from the husband’s death. The *kebele* [neighbourhood] didn’t take measure on this. The woman has to do a small business to sustain herself and her children.”

Woman living with HIV, Ethiopia

“ From now onwards, I do not have the hope of getting married and giving birth.”

Woman living with HIV, Ethiopia

“ After I gave birth, I didn’t breastfeed my child. One of the neighbours saw that I am not breast-feeding ... She disseminated the news to all. When my child gets sick, the owners came and told me to leave the compound.”

Woman living with HIV, Ethiopia



4. Rights

Evidence of the gender dimensions of HIV-related stigma included in relation to:

Abuse of rights: Women and men living with HIV reported similar levels of abuses of their rights, but differences were seen among those deciding not to seek legal redress. A higher proportion of women felt intimidated or scared to take action (29 per cent compared to 19 per cent of men), while a higher proportion of men feared that the process would be too bureaucratic (27 per cent compared to 16 per cent). In the group discussions, participants shared examples of female sex workers facing particularly strong HIV-related stigma, for example with those in Jijiga forced to have HIV tests and to leave town.

Support organizations: The majority of women (68 per cent per cent) – a slightly higher proportion than for men – were a member of a support organization for people living with HIV.

Policy commitments: A lower proportion of women had heard of Ethiopia’s national policy on HIV or the Declaration of Commitment on HIV.

Achieving change: Even more women than men (79 per cent versus 73 per cent) reported feeling that they do not have the power to influence decisions on policies or programmes affecting people living with HIV. The largest proportion of women (58 per cent) cited raising awareness of HIV among the public as the key strategy to address stigma.

“ Like any other human being, we take legal resort to stop the abuse and to protect our right.”
Woman living with HIV, Ethiopia

“ The stigma and discrimination leads me to further motivation to preserve my rights. I started going office to office and telling people about my rights. In order to stand for our rights, we get organized under an association.”
Woman living with HIV, Ethiopia

Figure 8: Actions by people living with HIV to confront stigma or affect change, Ethiopia

Action in the last 12 months	Female	Male
Confronted, challenged or educated someone who was stigmatizing	26%	27%
Know organizations or groups that can help if experienced stigma or discrimination	56%	59%
Sought help from any organization or groups to resolve an issue of stigma or discrimination	15%	18%
Supported other people living with HIV	58%	63%
Currently a member of a people living with HIV support group/network	68%	66%
Involved (as a volunteer or as an employee) in any programme or project that provides assistance to people living with HIV	26%	28%
Involved in any efforts to develop legislation, policies or guidelines related to HIV	9%	12%

ANALYSIS

What does this mean?

An analysis of the findings from the Stigma Index in Bangladesh, the Dominican Republic and Ethiopia identifies many commonalities, but also some differences, relating to the gender dimensions of HIV-related stigma in the three countries.

Based upon those, we have drawn the following top 10 conclusions:

- 1 **HIV-related stigma remains a harsh and forceful reality.** Often, women/girls and men/boys living with HIV experience similar, and often very significant, devaluation. Sometimes, the challenge of coping with the daily fear, ignorance and prejudice associated with the virus is a more common bond than gender is a divide.
- 2 However, the results of the Stigma Index in the three countries also clearly indicate that:
 - >> **Women can be affected by HIV-related stigma more than men.** For example, across the three countries, women living with HIV were more affected by community-level stigma. Multiple factors – from their cultural roles to higher levels of unemployment – meant that women were more exposed to ‘everyday’ discrimination by friends and neighbours, such as gossip and name calling. Women were also more likely to internalize such experiences as self-stigma. For example, in the Dominican Republic and Ethiopia, women experienced much higher levels of shame and lower levels of self-esteem than men.
 - >> **Women can be affected by HIV-related stigma less than men.** For example, in all three countries, men were more likely to be affected by discrimination within the context of formal work environments.
 - >> **Women can be affected by HIV-related stigma differently to men.** For example, while, in all three countries, both sexes tended to experience similar levels of HIV-related discrimination, the repercussions were often different – with women more likely to take negative, often drastic, decisions about their life choices as a result of being HIV-positive (see Figure 9).

Figure 9: Decisions taken as a result of being HIV-positive

Decisions taken by people living with HIV due to their HIV status	Bangladesh		Dominican Republic		Ethiopia	
	Female	Male	Female	Male	Female	Male
I decided not to get married	87%	71%	29%	19%	44%	23%
I decided not to have sex	37%	8%	28%	12%	48%	27%
I decided not to have (more) children	87%	84%	67%	51%	62%	52%

HIV-related stigma in the community – an experience from Bangladesh

“ My neighbours did not talk to me after I tested positive. I couldn’t bathe in the same pond as them. They turned away their faces.”

Woman living with HIV

- 3 **Women living with HIV are particularly strongly and disproportionately affected by HIV-related stigma within highly traditional and/or religious societies characterized by entrenched gender inequality.** Across the three countries, women shared traumatic experiences of being thrown out of their homes by their family or in-laws, being denied their property and inheritance rights or being treated as ‘sinful’ or ‘outcasts’. The existing low position of women was compounded by the prejudices and misconceptions associated with HIV.

4 Women living with HIV can be particularly vulnerable to the most severe, personal consequences of HIV-related stigma and discrimination. For example:

- >> In Bangladesh, nearly one fifth of women felt suicidal.
- >> In the Dominican Republic, 101 women out of 429 (24 per cent) had been coerced into sterilisation.
- >> In Ethiopia, denial of services had resulted in deaths.

Severe consequences of HIV-related discrimination – an experience from Ethiopia

“ In the hospital, the doctors were willing to make operation, but there were problem among the nurses. The HIV-positive woman gave birth through normal delivery. But there was a problem in the breathing system of the child ... he needed to take oxygen from the machine. Hence, the lady was waiting for the baby. In the meantime ... the woman who is HIV-negative came and gave birth. That child was also in need for the oxygen. The nurse took the oxygen from the child of the HIV-positive mother and gave to this second child. After 12 hours, the HIV-positive mother is told that her child has died.”

Woman living with HIV

5 Often, the very people who should support women living with HIV and address their specific needs, perpetrate high levels of HIV-related stigma. In all three countries, women shared experiences of discriminatory practices by health care workers, including abuse of their human rights through coercion into negative and/or unnecessary decisions relating to their SRHR (see Figure 10). In the case of Bangladesh, this contributed to the majority of women not disclosing their HIV status to their health worker and only seeking health services in extreme situations.

Figure 10: Advice and coercion by health workers relating to women’s SRHR choices

Actions by health workers reported by people living with HIV	Bangladesh		Dominican Republic		Ethiopia	
	Female	Male	Female	Male	Female	Male
Advice not to have a child	27%	22%	28%	16%	44%	37%
Coercion into sterilisation	1%	1%	20%	3%	4%	3%
Coercion into termination of pregnancy	2%	-	0%	-	2%	-
Coercion into method to give birth	2%	-	5%	-	5%	-
Coercion into infant feeding practice	13%	-	6%	-	7%	-

6 The gender dimensions of HIV-related stigma are shaped by and, in turn, influence the context of and national response to HIV. For example, in Bangladesh – a country with high levels of poverty and low HIV prevalence – the gender dimensions are affected by:

- >> **Awareness of HIV:** With little understanding of the facts about HIV transmission, community members routinely carry out discriminatory acts (such as not touching women who are HIV-positive), while women living with HIV themselves perpetuate stigma (for example by isolating themselves in their house).
- >> **Patterns of HIV transmission:** For example, within an epidemic where HIV is strongly associated with migrant work by men, most women had an HIV test due to their husband or male partner having already tested HIV-positive and most blamed others for their HIV status.
- >> **National protocols:** Women living with HIV experience lack of essential HIV-related services that are not yet fully integrated into standard packages of government health care. For example, a large proportion of women reported being refused ART for PMTCT.

7

Women living with HIV are particularly vulnerable to HIV-related stigma when they come into contact with sexual and reproductive health services. Across the countries, this was seen in relation to areas such as: sexuality (with higher numbers of women deciding not to have sex); decisions about reproduction (with higher numbers of women deciding not to have children); delivery (with reports of women being denied the safest options for birth); and breastfeeding (with women fearing the visibility and isolation of using formula feeding). Also, women are particularly vulnerable to HIV-related stigma affecting their children, including those that are living with HIV. Across the countries, women shared experiences of where HIV status – either their own or that of their child – had caused children to experience discrimination, in turn producing intense fear and concern in their mothers.

Impact of HIV-related stigma on women as mothers

“ My uncle notified the police and other highly-placed people in our community about my physical condition. They took my two children and me away and kept us locked in a room in the office for disabled people for one month and two days. During this time nobody spoke to us or fed us regularly. I then felt like strangling my two children and blaming it on the people who locked us up, so that they would set me free.”

Woman living with HIV, Bangladesh

“ I fear that my children will face discrimination ... that they will be pulled out of school. I fear that, when they go to a hospital, they will not be seen.”

Woman living with HIV, Dominican Republic

“ I have a six-year[old] daughter and both adults and the children are insulting her. They told her that her mother is ‘aidsome’ and her father has died of AIDS. The children didn’t allow her to play with them ... I am worried because the situation might affect the mind of my children.”

Woman living with HIV, Ethiopia

8

Women’s most intimate relationship is a critical factor in their experience of HIV-related stigma. While some women described supportive relationships, others reported incidents of rejection, verbal abuse and violence. For example:

- >> In Bangladesh, the data showed that the majority of women had taken an HIV test due to their husband already being HIV-positive.
- >> In the Dominican Republic, women were more likely than men to receive a discriminatory/very discriminatory response when disclosing their HIV status to their partner.
- >> In Ethiopia, sero-discordant couples were more likely to divorce if the woman was HIV-positive.

9

Despite quite high knowledge of local support groups for people living with HIV, **women often have low levels of understanding of or engagement with the systems, policies and structures designed to support them**, such as international policy commitments and national HIV programmes. They also indicated lower confidence than men in their ability to influence change for people living with HIV.

10

Participation in an initiative like the People Living with HIV Stigma Index provides women living with HIV with a rare, sometimes unique, opportunity to share their experiences of the gender dimensions of HIV-related stigma. It also produces concrete data – both quantitative and qualitative – that provides unprecedented evidence of what this issue means and why it matters.

Using the Stigma Index to inform advocacy – experiences from the Dominican Republic

“ It has been empowering to talk to people about their rights. We have new friends, new partners, and my personal hope is that this will help us eliminate stigma.”

Woman living with HIV

“ As an activist and as practitioner in the Dominican Republic, I want to use the findings from the Index to make definite recommendations for policies.”

Woman living with HIV

RESOURCES

What's out there?

What is it called?	When was it produced?	Who produced it?	What is it?	Where can it be found?
The People Living with HIV Stigma Index	2008	<i>International Planned Parenthood Federation, Global Network of People Living with HIV, International Community of Women Living with HIV and Joint United Nations Programme on HIV/AIDS</i>	Website for the Stigma Index, providing: an introduction to the Stigma Index; updates on where the Stigma Index is being rolled out; downloadable resources, such as the User Guide; and information about partner organizations.	www.stigmaindex.org
The Data Centre	Forthcoming in 2011	IPPF	Online facility to enable easy extraction of statistics from the People Living with HIV Stigma Index from any given country.	www.stigmaindex.org
The People Living with HIV Stigma Index: An Index to Measure the Stigma and Discrimination Experienced by People Living with HIV	February 2008	<i>International Planned Parenthood Federation, Global Network of People Living with HIV, International Community of Women Living with HIV and Joint United Nations Programme on HIV/AIDS</i>	User Guide for teams implementing the Stigma Index. Contains: background information on the Stigma Index; introduction to the questionnaire and data gathering process; and practical guidance for training interviewers, including in relation to ethical standards and data entry and analysis. Also includes tips for communicating the research findings and using them to advocate for the rights of people living with HIV.	www.stigmaindex.org
Understanding and Challenging Stigma Toolkit	2007 (revised edition)	<i>International HIV/AIDS Alliance, International Centre for Research on Women, Academy for Educational Development and PACT Tanzania</i>	Toolkit by and for HIV trainers in Africa for planning and organizing educational sessions with community leaders or groups. Contains over 100 participatory exercises and sets of pictures codes to identify stigma, discuss the rights of people living with HIV and stimulate discussions on gender, sexuality and morality. Includes modules on stigma relating to children/youth and men who have sex with men.	www.aidsalliance.org
Self-Assessment Checklist: Stigma and Discrimination		<i>NGO Code of Good Practice for NGOs Responding to HIV/AIDS</i>	Tool to support NGOs to measure their programmes from the perspective of stigma and discrimination – in relation to the principles of the Code of Good Practice (developed by civil society organizations to provide a shared vision of good practice in HIV programming and advocacy).	www.hivcode.org
HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes	2005	<i>Joint United Nations Programme on HIV/AIDS</i>	Best practice guide sharing case studies from multiple countries – including Brazil, Cambodia, Belarus and Zambia – of programmes addressing HIV-related stigma. Includes analysis of the root causes and impacts of stigma, including in the context of gender and key populations. Identifies key entry points for successful responses.	www.unaids.org

What is it called?	When was it produced?	Who produced it?	What is it?	Where can it be found?
Non-Discrimination in HIV Responses	2010	<i>UNAIDS</i>	Paper to the 26th Meeting of the UNAIDS Board providing an overview of HIV-related stigma and exploring its different impacts, including on women and girls and key populations. Shares challenges and successful approaches to programming for HIV-related stigma reduction and provides recommendations, including on addressing the gender dimensions and building evidence.	www.unaids.org
Modelling the Impact of Stigma on HIV and AIDS Programmes: Preliminary Projections for Mother-to-Child Transmission	2010	<i>International Centre for Research on Women and London School of Hygiene and Tropical Medicine</i>	Analysis taking an initial step toward quantifying how stigma undermines HIV programmes – by estimating the potential impact of stigma on the effectiveness of mother-to-child HIV prevention programmes. Findings suggest that stigma can have a large impact on mother-to-child transmission and programmes that can effectively reduce stigma will be beneficial to women and children.	www.icrw.org
HIV-Related Stigma Measures and Measurement Tools	2010	<i>Global Network of People Living with HIV</i>	Report of an online consultation and in-depth interviews with people living with HIV as part of a process to develop better indicators to measure HIV-related.	www.gnpplus.net
10 Reasons Why the Criminalization of HIV Exposure or Transmission Harms Women	2009	<i>ATHENA Network, AIDS Legal Network and AIDS and Rights Alliance for Southern Africa</i>	Document detailing how the application of criminal law to HIV exposure or transmission – far from providing justice to women – endangers and further oppresses them.	www.athenanetwork.org
Verdict on a Virus	2008	<i>International Planned Parenthood Federation</i>	Booklet giving information about the criminalization of HIV transmission or exposure and the related health, human rights and legal implications.	www.ippf.org
Transforming the National AIDS Response: Advancing Women's Leadership and Participation	2010	<i>UNIFEM and Athena Network</i>	Resource guide highlighting strategies for incorporating gender equality and women's rights into national responses to HIV. Discusses various approaches for advancing women's leadership and the meaningful participation of women living with HIV.	www.athenanetwork.org
Report on the findings of the People Living with HIV Stigma Index	(To be published in 2011)	<i>Network of Networks of HIV Positives in Ethiopia</i>	Presentation of the findings from the People Living with HIV Stigma Index in Ethiopia and some analysis, including from a gender perspective.	www.nepplus.org
Republica Dominicana: Estigma y Discriminación en Personas que Viven con el VIH	April 2009	<i>Francisco Caceres Ureña</i>	Presentation of the findings from the People Living with HIV Stigma Index in the Dominican Republic and some analysis, including from a gender perspective.	www.profamilia.org
People living with HIV Stigma Index Study in Bangladesh	2009	<i>James P Grant School of Public Health. BRAC University, Bangladesh</i>	Presentation of the findings from the People Living with HIV Stigma Index in Bangladesh and some analysis, including from a gender perspective.	www.stigmaindex.org

CALL TO ACTION

What needs to happen?

International donors, global policy-makers, national governments, academic institutions, programme managers, civil society and people living with HIV are called upon to:

- 1 Understand how HIV-related stigma can affect women and girls living with HIV more, less or differently than men and boys.** Recognize that this is rooted in entrenched gender dynamics and inequalities that often make women significantly more vulnerable to the impact of stigma at all levels.
- 2 Document evidence of the complex ‘jigsaw’ of the gender dimensions of HIV-related stigma, within a ‘know your epidemic’ approach to HIV.** Support the roll-out and, critically, follow up on the People Living with HIV Stigma Index. Ensure that, within that and other research processes, the nuances of inequality are addressed, including by gathering sex- and age-disaggregated quantitative and qualitative data.
- 3 Involve and empower women and girls living with HIV at the heart of action** to address stigma and throughout the cycle of programme and advocacy design, implementation and monitoring. Put the greater involvement of people living with HIV (GIPA) principle into practice.
- 4 Review existing policies and procedures** – from donors’ funding criteria to governments’ national strategies for HIV and health services’ guidelines for service provision – to assess whether they respond to the gender dimensions of HIV-related stigma and to make changes accordingly.
- 5 Respond to specific contexts and needs relating to the gender dimensions of HIV-related stigma.** For example, design programmes that maximize the strengths of local cultures, are rights-based, bring women/girls and men/boys together and work towards gender transformation in the context of HIV.
- 6 Advocate on the gender dimensions of HIV-related stigma within all relevant forums** – from local support groups for people living with HIV to national planning processes and global policy-making. Explain why – within trends towards wider responses to health and health systems strengthening – action on this area is ‘money well spent’ and fundamental to achieving universal access to HIV prevention, care, support and treatment and the Millennium Development Goals.
- 7 Challenge entrenched inequalities at personal, institutional and structural levels.** For example, work with community gatekeepers and national leaders to ‘keep the best, change the rest’ of practices and systems that fuel stigma related to gender, HIV and key populations.
- 8 Share good practice and successful action** – maximising resources and avoiding ‘reinventing the wheel’.
- 9 Resource responses to the gender dimensions of HIV-related stigma.** Mobilize and/or provide adequate funding. Also ensure capacity building of women living with HIV (such as in human rights and advocacy) and health workers (such as in gender sensitivity and confidentiality).
- 10 Collaborate to build a broad-based movement of stakeholders** committed to action on the gender dimensions of HIV-related stigma. For example, mobilize women’s groups to advocate on HIV-related stigma, while mobilizing HIV groups to advocate on gender-related stigma.

Acknowledgements

This report was produced thanks to the experience, ideas and input of many different people and organizations.

The key contributors were Kevin Osborne and Liz Tremlett at the International Planned Parenthood Federation (IPPF) and Alice Welbourn, Fiona Hale and MariJo Vazquez at Salamander Trust Associates.

The reviewers included: Samanta Sokolowski and Ramona Wong-Grünwald, Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ); Lucy Stackpool-Moore, Rachel Lander and Daniel McCartney of the International Planned Parenthood Federation; Beri Hull and Ginna Anderson, International Community of Women Living with HIV; Habiba Akter, the Ashar Alo Society of Bangladesh; Tony Gomes (Consultant Bangladesh); Dulce Almonte, the Dominican Network of People Living with HIV (REDOVIH); Yilka Ademe, the Network of Networks of HIV Positives in Ethiopia (NEP+); Tsegazeab Bezabih (Consultant Ethiopia); and members of the Global Coalition on Women and AIDS including: Anna Forbes; Lynn Collins, the United Nations Population Fund; Robert Carr, the International Council of AIDS Service Organisations; Nazneen Damji, United Nations Entity for Gender Equality and the Empowerment of Women and Juliette Papy, Rodrigo Pascal and Jaime Todd-Gher of UNAIDS.

In addition, many thanks to the various country partners and participants that carried out the People Living with HIV Stigma Index in Bangladesh, the Dominican Republic and Ethiopia.

This report was written by Sarah Middleton-Lee (independent consultant) and designed by Jane Shepherd. Published in March 2011 by the International Planned Parenthood Federation.

Funding to support this work comes from the German Federal Ministry for Economic Cooperation and Development (BMZ) as part of a Grant Agreement between IPPF and the German BACKUP Initiative (GIZ) in Eschborn, Germany.

Photos by: Front cover left to right: IPPF/Chloe Hall/Ethiopia/2005; IPPF/Peter Caton/Bangladesh/2009; IPPF/Jon Spaul/Colombia/2006; IPPF/Veronica Gardenia/Sudan/2006. Back cover left to right: IPPF/Peter Caton/India/2006; IPPF/Adam Garner; IPPF/Chloe Hall/Ethiopia/2005; IPPF/Peter Caton/Nepal/2007; IPPF/Jenny Mathews/Bangladesh/2001. Page 12, IPPF/Peter Caton/Bangladesh/2009; page 15, IPPF/Peter Caton/Bangladesh/2009; page 17, Vanessa Kurz; page 22, IPPF/Chloe Hall/Ethiopia/2005.

IPPF Central Office is a signatory to the CONCORD European-wide NGO Code of Conduct on the use of photographs and images and is committed to upholding its principles. The photographs used in this publication are for illustrative purposes only; they do not imply any particular attitudes, behaviour or actions on the part of any person who appears in the photographs.

