

# Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV

**\*A Guidance Package**



# **Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV**

**\*A Guidance Package**

Published by:  
The Global Network of People Living with HIV/AIDS (GNP+)  
P.O. BOX 11726  
1001 GS Amsterdam  
The Netherlands

Website: [www.gnpplus.net](http://www.gnpplus.net)  
E-mail: [infognp@gnpplus.net](mailto:infognp@gnpplus.net)

Some rights reserved: This document may be freely shared, copied, translated, reviewed and distributed, in part or in whole, but not for sale or use in conjunction with commercial purposes. Only authorised translation, adaptation and reprints may bear the emblems of GNP+ and/or individual partners to the Guidance Package. Enquiries should be addressed to GNP+, P.O. BOX 11726, 1001 GS, Amsterdam, The Netherlands, [infognp@gnpplus.net](mailto:infognp@gnpplus.net).

© May 2009. The Global Network of People Living with HIV/AIDS (GNP+)

Design: [www.samgobin.nl](http://www.samgobin.nl)

ISBN 978-94-90241-01-8

Suggested citation: GNP+, ICW, Young Positives, EngenderHealth, IPPF, UNAIDS. 2009. Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV: A Guidance Package. Amsterdam, GNP+.

# CONTENTS

ACKNOWLEDGEMENTS	5	Family planning and abortion	32
LIST OF ACRONYMS AND ABBREVIATIONS	6	Marriage, divorce, and child custody	33
EXECUTIVE SUMMARY	7	Women's property and inheritance rights	33
		Male circumcision	34
		The greater involvement of people living with HIV	34
1 INTRODUCTION AND RECOMMENDATIONS	9	II. Policies Affecting Key Populations At Higher Risk	34
		Young people	34
I. Towards a Better Understanding of the Sexual and Reproductive Rights of People Living with HIV	10	Sex workers	35
II. Overview of the Guidance Package	11	Drug users	36
III. Specific Recommendations	12	Men who have sex with men	37
		Transgender People	37
2 CREATING A SUPPORTIVE HEALTH SYSTEM	14	Prisoners	38
		Migrants	38
I. Structural Issues	16	III. Linking Legal Reforms to Sexual and Reproductive Health	39
Financing	16		
Linking services	16	4 EFFECTIVE ADVOCACY	41
Supplies and technologies	17		
Health care workers	18	I. Challenges To Effective Advocacy	42
HIV Stigma and discrimination	19	HIV stigma and discrimination	43
Non-state actors: community organisations and informal health workers	19	Gender inequality and violence	43
Reaching marginalised populations	20	Marginalisation	44
Monitoring and evaluation	20	Poverty	45
II. Clinical Services	20	Lack of collaboration	45
HIV testing and counselling	21	II. Improving Advocacy	46
Sex education	22	Rely on the unique expertise of people living with HIV	46
Psychosocial support	23	Provide education and training	46
Family planning and dual protection	23	Collect policy-relevant evidence	47
Abortion	24	Monitor and evaluate	48
Conception, pregnancy and childbirth	25	Strengthen networks and alliances	49
Sexually transmitted infections	26	III. Empowerment and Health Through More Effective Advocacy	49
Cancer diagnosis and treatment	26		
Violence	27	APPENDIXES	
Sexual dysfunction	27	More Information And Useful Tools	53
Positive prevention	28	List of Recommendations	56
III. Protecting Human Rights, Advancing Public Health	28		
		ENDNOTES	58
3 LEGAL AND POLICY CONSIDERATIONS	29		
		PHOTO CREDITS	63
I. Sexual and Reproductive Health-Related Laws and Policies	31		
Criminalisation of HIV transmission	31		
Anal sex	31		
HIV testing and counselling	32		



## ACKNOWLEDGEMENTS

This Guidance Package is the result of extensive work on the part of many people. It grew out of a collaborative process among eight organizations: Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV/AIDS (ICW), Young Positives, EngenderHealth, International Planned Parenthood Federation (IPPF), the Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Population Fund (UNFPA) and the World Health Organization (WHO). This process began with a consultation on the rights of people living with HIV to sexual and reproductive health held in Addis Ababa in March 2006 and sponsored by EngenderHealth, UNFPA and WHO. The Guidance Package was presented in draft form at two subsequent international meetings by and for HIV-positive people supported by the agencies listed above as well as other partners: the Global Consultation on the Sexual and Reproductive Health and Rights of People Living with HIV held in Amsterdam, December 2007 and at the LIVING 2008: The Positive Leadership Summit just prior to the XVII International AIDS Conference in Mexico City.

Andrew Doupe, Kate Hawkins and Susan Paxton prepared the first drafts of the different chapters. Jennifer Nadeau undertook the challenging task of boiling down 400 pages into the concise document it is. Input, comments, suggestions and support were given by many people including: Emma Bell, Lynn Collins, Jane Cottingham, Raoul Fransen, Beri Hull, Manjula Lusti-Narasimhan, Kevin Moody, Promise Mthembu, Kevin Osborne, Paul Perchal, Jason Sigurdson, Kate Thomson, Susan Timberlake, Danielle Turnipseed, Alejandra Trossero and Françoise Welter.

We gratefully acknowledge the support of the following organisations to various steps in the process of producing this Guidance Package: Aids Fonds Netherlands, EngenderHealth, the Ford Foundation, the William and Flora Hewlett Foundation, the Netherlands Ministry of Foreign Affairs, the David & Lucile Packard Foundation, Soa Aids Nederland, UNFPA and WHO.

## LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
CCM	Country Coordinating Mechanism
GBV	Gender-Based Violence
GIPA	Greater Involvement of People living with HIV
Global Fund	The Global Fund to fight AIDS, Tuberculosis and Malaria
GNP+	The Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
HPV	Human Papillomavirus
ICW	International Community of Women Living with HIV/AIDS
IPPF	International Planned Parenthood Federation
IUD	Intra-Uterine Device
LGBT	Lesbian, Gay, Bisexual, Transgender and intersex
MDG	Millennium Development Goal
MSM	Men who have Sex with Men
NAPWA	Australian National Association of People living with HIV
NGO	Nongovernmental Organisation
NWHN	Namibia Women's Health Network
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	People Living with HIV
PPTCT	Prevention of Parent-To-Child Transmission
PRS	Poverty Reduction Strategy
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
STI	Sexually Transmitted Infection
SWAp	Sector Wide Approach
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization



## EXECUTIVE SUMMARY

Imperatives of both human rights and public health require that health care and legal systems support the sexual and reproductive health and rights of people living with HIV. People living with HIV have the right to healthy, satisfying sex lives, and need laws to protect this right and appropriate services to ensure their sexual and reproductive health. From a public health perspective, decision-makers and service providers must recognize that people living with HIV do enter into relationships, have sex, and bear children. Ensuring that they can do these things safely is key to maintaining their own health, and that of their partners and families.

People living with HIV developed this Guidance Package to help policymakers, programme managers, health professionals, donors, and advocates better understand the specific steps that must be taken to support their sexual and reproductive health and rights. The Guidance Package casts a wide net, examining the sexual and reproductive health benefits of reforms in diverse sectors. It makes 12 recommendations, which encompass – and, in many cases, cut across – changes that must be made in health services, in the policy and legal arena, and in advocacy efforts.

The overall weakness of health systems is responsible for many of the gaps that impede the full enjoyment by people living with HIV of their sexual and reproductive health and rights. Building up health systems, and improving access to widely needed sexual and reproductive health services – for example, male and female condoms – is critically important. People living with HIV also need special sexual and reproductive health-related services, such as guidance on using hormonal contraceptives while on antiretroviral therapy. Further, stigma and discrimination may make it difficult for people who are HIV-positive to access health services. Health workers need resources, information, skills and sensitivity training related to the specific needs of HIV-positive people, including the importance of confidentiality and how to minimize the small risk of occupational exposure to HIV infection.

Legally, the issue most fundamental to the sexual and reproductive health of people living with HIV is the clear, enforced prohibition of discrimination. Second, governments should refrain from criminalizing sexual behaviour among consenting adults in private, such as laws relating to anal sex, fornication and adultery. The transmission of HIV should not be considered a crime, except for the very rare cases where there is evidence beyond a reasonable doubt that one person

deliberately tried to infect another and indeed did so. Beyond this, laws and policies in many areas – including those related to HIV testing and counselling, family planning, childbearing and childcare, marriage, property and inheritance rights, and male circumcision – can directly or indirectly affect the sexual and reproductive health of people living with HIV, and should be examined to ensure they are supportive of their health and human rights. Members of marginalised groups are often at particular risk of HIV infection and, once they become HIV-positive, have an especially difficult time getting the support they need. Legal systems should provide special protection for marginalised groups, as well as access to quality legal services so that alleged human rights violations can be appropriately addressed.

The advocacy agenda of people living with HIV to promote their sexual and reproductive health and rights is focused largely on reform of health and legal systems and strengthening of community systems. Advocates need to work with and beyond health and legal systems to fight stigma and discrimination against people living with HIV, patriarchal attitudes toward women, paternalism towards young people, the marginalisation of people most vulnerable to HIV, persistent poverty, and a lack of coordination and collaboration – all of which can undermine sexual and reproductive health and the enjoyment of human rights.

The vital importance of involving people living with HIV underlies every recommendation in this Guidance Package. People living with HIV should be consulted in designing relevant policies and programmes: They know their own sexual and reproductive health needs, aspirations and desires; speak from experience about where and how existing structures have failed to meet these needs; and active participation can itself advance sexual and reproductive health and rights as it tends to diminish stigma and empower HIV-positive people to seek the support that they need.

This Guidance Package, developed by people living with HIV, describes the important issues and key areas for change. Going forward, legislators, government ministries, international organizations, donors, and community- and faith-based organizations, with the continued input and guidance of people living with HIV, must work together to put in place the services and legal supports that will build better sexual and reproductive health for everyone.







# 1

## INTRODUCTION AND RECOMMENDATIONS

It is estimated that 33 million people are living with HIV. More and more of them are accessing antiretroviral treatment, extending their lives and their productivity. An important part of their lives, as for any human being, is sexuality and reproduction. Like everyone else, they have a right to a satisfying, safe and healthy sexuality and reproductive health. This Guidance Package is intended to help anyone concerned with public health and human rights – whether as a health professional, a policymaker or an advocate – better understand *why* and *how* to meet the sexual and reproductive health needs of people living with HIV. It shows that greater attention to human rights is critical to sexual and reproductive health and the general wellbeing of people living with HIV, making lives longer, healthier, more productive, and more satisfying. Addressing sexual and reproductive health and human rights is also key to slowing the spread of the epidemic by preventing new infections. In all these ways, individuals, families, and societies benefit.

For too long, the sexual and reproductive health and rights of people living with HIV received little attention. A positive HIV test was taken to mean the end of a person's sex life. In reality, of course, people living with HIV have always wanted – and deserved – to have healthy, satisfying sex lives; to bear and raise children; and to protect themselves and their partners from unwanted pregnancies and sexually transmitted infections (STIs), including HIV. Yet for too

long policy debates have largely ignored the sexuality of people living with HIV, and programmes – to the extent they addressed sex and reproduction at all – were generally limited to helping pregnant women avoid transmitting the virus to their children.

Several factors, however, have moved the international community to consider ways to meet broader needs. First, sexual and reproductive health in general has received increased global attention in the years following the 1994 International Conference on Population and Development (the 'Cairo Conference'). Many advocates have pointed out that improved sexual and reproductive health are essential to meeting the Millennium Development Goals (MDGs)<sup>1</sup> agreed to by world leaders in 2001. At the 2005 World Summit of the United Nations General Assembly, United Nations member States committed to achieve universal access to reproductive health by 2015 as a means to reaching the MDGs.<sup>2</sup> While people living with HIV are not always explicitly referred to in these discussions, the new emphasis on sexual and reproductive health influences HIV-related programme planning.

Second, from a programmatic perspective, there has been increasing attention given to the benefits of better integrating HIV and sexual and reproductive health information and services, which have often developed parallel infrastructures. In some cases, these two health systems offer similar or identical services at different sites. In other cases, the narrow focus of each system can make it difficult for either one to meet all of their clients' needs – for example, an HIV clinic may not be able to provide women with counselling about a full range of contraceptive methods, while a reproductive health clinic may not offer voluntary HIV counselling and testing. This means that people must seek out services at separate centres rather than accessing what they need all in one place. Advocates and programme managers are now actively seeking ways to take advantage of synergies to provide more efficient and more comprehensive care.

Third, the wider availability of affordable antiretroviral therapy means that people are living longer, healthier lives with HIV. As more and more people worldwide are managing HIV infection as a chronic disease, advocates and health professionals have begun to focus on improving the *quality* of life with the virus – including improved sexual and reproductive health. People who are HIV-positive need

prevention programmes to help them stay healthy, avoid STIs and protect their partners from HIV infection.

Positive prevention strategies represent a fourth factor in the greater push for improved sexual and reproductive health. These programmes are a critical component of efforts to reach universal access to HIV prevention, treatment, care and support. It is imperative that positive prevention strategies be responsive to and compatible with the practical realities people living with HIV face in trying to protect themselves and others. They must protect people living with HIV from discrimination and empower them with the necessary information, treatment, services and commodities and to be able to avoid the onward transmission of HIV, including through reducing infectiousness through antiretroviral treatment under optimal conditions.<sup>3</sup> People living with HIV need to lead in developing such strategies.

## **I. Towards a Better Understanding of the Sexual and Reproductive Rights of People Living with HIV**

The sexual and reproductive health of people living with HIV are increasingly being addressed in discussions among policymakers, programme planners and civil society organizations, and in the policy analyses they undertake. The International Community of Women Living with HIV/AIDS (ICW) has conducted extensive research and advocacy work to improve the sexual and reproductive health of women living with HIV, and, in partnership with other organisations, has offered workshops on reproductive rights at the International AIDS Conference in Toronto in 2006 and the International Women's Summit in Nairobi in 2007. In 2006, the World Health Organization (WHO) and the United Nations Population Fund (UNFPA) published guidelines on sexual and reproductive health care for women living with HIV.<sup>4</sup>

Also in 2006, EngenderHealth, UNFPA, and WHO, with input and participation from ICW, the Global Network of People Living with HIV (GNP+), and Young Positives, convened a global consultation in Addis Ababa on the rights of people living with HIV to sexual and reproductive health.<sup>5</sup> In 2007, the journal *Reproductive Health Matters* drew from papers prepared for the Addis Ababa meeting for a special

supplement on the sexual and reproductive health needs of people living with HIV. All these efforts have helped expand and deepen the understanding of the issues. However, participants at the Addis Ababa consultation agreed that further discussions should be convened and led by people living with HIV themselves.

In response, GNP+, ICW and Young Positives organised in 2007 a Global Consultation on the Sexual and Reproductive Health and Rights of People Living with HIV in Amsterdam. This Consultation brought together 65 representatives of organisations of people living with HIV from around the world and allies focused on research, policy analysis, advocacy, and education. The Global Consultation had several goals:

- To strengthen the capacity of individuals living with HIV and their organisations and networks to participate fully in policy and programme design;
- To articulate an overarching position statement on the sexual and reproductive health and rights of people living with HIV;
- To highlight the specific sexual and reproductive health needs of key groups;
- To stress the gender dimensions of the sexual and reproductive health of people living with HIV, and the overlapping issues of violence and poverty; and
- To identify a concrete agenda for further debate, research, and action.

In preparation for the Consultation, the organisers commissioned background papers on three key areas where progress must be made to ensure sexual and reproductive health and rights for people living with HIV: health systems, law and policy, and advocacy. Participants reviewed and discussed these papers, but the conversation also drew upon participants' own experiences as individuals and advocates. Participants were organised in thematic working groups focused on women, men, vulnerable groups (including sex workers, injecting drug users, and transgender people), and youth to ensure that sexual and reproductive health concerns were approached from diverse perspectives.

At the conclusion of the Consultation, participants asserted their view that the protection of the sexual and reproductive health and rights of people living with HIV must be a collective responsibility, shared among governments; international and regional organisations; donors; service

providers; nongovernmental, community-based, and faith-based organisations; and people living with HIV. They also presented a list of 39 recommendations, focusing specifically on the involvement and inclusion of people living with HIV, issues of stigma and discrimination, priority research issues, and responsibilities and choices. Following the Consultation, these recommendations were reviewed and refined in consultation with each participant's constituencies.

Despite growing awareness of how sexual and reproductive health care for people living with HIV is essential to ensuring both human rights and public health, effective and scaled-up policies and programmes remain scarce. Improving this situation will require a multi-pronged approach that takes into account issues of gender, violence, poverty, stigma, and discrimination, as well as health care supplies and services. It will have to take place in cultural environments where talking about sex is taboo and people of all ages have difficulty getting the information and counselling they need to make informed decisions about their sexuality and fertility. And it will have to find ways to deliver information and services to marginalised groups including sex workers, injecting drug users, prisoners, migrants, refugees, and members of lesbian, gay, bisexual, transgender and intersex communities.

This Guidance Package aims to take these complexities into account while moving the field beyond conversation into action. Working together, with the help of this Guidance Package, people around the world in varied roles and with different backgrounds and perspectives can advance sexual and reproductive health and human rights and help people living with HIV live better, safer, and healthier lives. Both public health and human rights imperatives demand that we take these next steps forward.

## II. Overview of the Guidance Package

This Guidance Package consolidates the main points of the three background papers drafted in advance of the Consultation into a single guide with clear, concise recommendations for health professionals, programme managers, policymakers, donors, and advocates. While it is informed by the outcomes of the Global Consultation, it should not be read as a summary of the findings and recommendations of the Consultation (These have been

published elsewhere<sup>6</sup>, and will form the basis for an Advocacy Agenda to be implemented by the networks and organizations of people living with HIV themselves). The Guidance Package reflects a comprehensive, two-year process of research and analysis led by GNP+, ICW, and Young Positives, in collaboration with EngenderHealth, the International Planned Parenthood Federation (IPPF), UNAIDS, UNFPA, and WHO, with input from HIV-positive networks worldwide. It explains what global stakeholders in the areas of health, policy, and advocacy can do to support and advance the sexual and reproductive health of people living with HIV, and why this matters.

*Chapter Two* of the Guidance Package focuses on health systems, which – particularly in low-income countries – are currently inadequate to meet the needs of their populations. Support for the sexual and reproductive health of people living with HIV requires a specific set of services, including the diagnosis, management, and treatment of HIV and other STIs; sex education and information; psychosocial support to cope with living with HIV; family planning; safe abortion and/or post-abortion care; services to assist conception; antenatal, delivery, and postnatal services; cancer diagnosis and treatment; services to address gender- and sexuality-based violence; counselling and treatment to address sexual dysfunction; and information, services, commodities and social support for HIV prevention.

*Chapter Three* addresses the policy and legal arena. Here, the most basic need is for laws that prohibit discrimination against people living with HIV, that these laws are known and enforced, and that people living with HIV can access necessary legal support. Protective laws based on recognised human rights standards can help people living with HIV to obtain sexual and reproductive health care, as well as employment, education, health insurance, legal aid, housing, treatment, and other social entitlements. Governments can also develop and implement national frameworks and guidelines that explicitly protect the sexual and reproductive health of people living with HIV.



Finally, numerous specific laws and policies can directly affect the sexual and reproductive health of people living with HIV, such as those related to HIV testing and counselling, residence requirements for obtaining health services, the criminalisation of HIV transmission or prohibitions on sex between consenting adults of the same sex. By reforming these laws, governments can make great strides in enabling people living with HIV to get the information and services they need to protect their own health and the health of others.

*Chapter Four* examines advocacy opportunities and challenges. Advocates must continue to press for greater political attention and commitment to sexual and reproductive health in order to combat HIV. Yet they must also contend with – and struggle against – a host of other social and economic barriers, including stigma and discrimination, gender inequality, violence, marginalisation, and poverty. Advocacy organisations need to work internally as well as externally to overcome these barriers and ensure a comprehensive, inclusive agenda. The chapter also suggests a set of tools and approaches that advocates can use to strengthen their voices, including education and training, research evidence, existing and new monitoring tools, and alliances.

Finally, the Guidance Package includes an *Appendix* with information on useful resources and tools related to the sexual and reproductive health and rights of people living with HIV.

Health systems, legal systems, and advocacy are intertwined and, in many cases, action will be required on all three fronts to achieve effective change. For example, ensuring that HIV testing advances (rather than undermines) sexual and reproductive health will require training for health workers in ensuring non-discrimination, informed consent and confidentiality, and providing ongoing support and counselling. It will also require laws that prohibit mandatory testing and disclosure, protect confidentiality, and guarantee non-discrimination for those who choose to disclose their status. And it will require advocates to monitor adherence to such policies and protest against human rights abuses, including by using available legal channels (e.g., courts, human rights commission, ombudsman) to demand appropriate redress.

### III. SPECIFIC RECOMMENDATIONS

Collectively, the three following chapters of this Guidance Package support 12 cross-cutting recommendations:

1. HIV testing should never be mandatory and always be based on the ‘three Cs’: confidential, based on informed consent, and conducted with counselling. This applies equally to marginalised groups, including sex workers, injecting drug users, prisoners, migrants, refugees, and members of lesbian, gay, bisexual, and transgender and intersex communities.
2. Systems for HIV prevention, treatment, care, and support must be strengthened to deal with increased demand *at the same time that* HIV testing is scaled up, to ensure that HIV testing results in referral to HIV prevention, treatment, care and support programmes. In particular, pregnant women should not be tested only to prevent transmission from parent to child; they must also be offered prevention, treatment and care services.
3. National laws should be reformed and enforced to ensure that:
  - Laws explicitly ban discrimination based on sexual orientation, gender identity, and HIV status;
  - Anal sex, sex work, same-sex relationships, and transgender relationships are decriminalized;
  - Disclosure of HIV status is not required by law if a person is practicing safer sex, their HIV status is otherwise known, or there is a well founded fear of harm by the other person;
  - HIV transmission is not considered a crime except for rare cases where there is evidence beyond a reasonable doubt that one person deliberately tried to infect another and indeed did so;
  - HIV status alone does not affect a person’s right to marry or found a family, is not grounds for divorce, and is not relevant in child custody decisions;
  - Young people have the right to confidentiality and do not need parental permission for age-appropriate information and sexual and reproductive health care, even if they are below the age of majority;
  - Women’s property rights are ensured and protected, particularly following divorce, abandonment or a spouse’s death;

- Sexual violence, including incest, forced or early marriage, sexual assault or rape (including in the context of sex work or in marriage) is recognised and prosecuted as a crime;
  - Injecting drug users are provided with treatment, including opioid substitution therapy, and harm reduction programmes as an alternative to incarceration; and
  - Transgender people are legally recognised and clear procedures are in place for changing name and sex on official documents.
4. All people living with HIV – including members of marginalised groups, such as sex workers, injecting drug users, prisoners, migrants, refugees, and members of lesbian, gay, bisexual, transgender and intersex communities – should have access to a full range of sexual and reproductive health services, including:
    - All available contraceptive options and help with dual protection<sup>7</sup>, without coercion toward any method;
    - Counselling and support for positive prevention and voluntary disclosure
    - Access to safe abortion (where legal) and post-abortion care;
    - Counselling and support for safe ways to become pregnant;
    - Counselling and practical support for infant feeding, whether breastfeeding or replacement feeding;
    - Diagnosis and treatment of STIs;
    - Cancer prevention and care;
    - Counselling related to violence;
    - Sexual dysfunction treatment; and
    - Male circumcision for men living with HIV if, when fully informed, they want the procedure.
  5. Health workers should receive training in human rights and universal precautions, as well as specific training in sexual and reproductive health care for people living with HIV, including technical skills and stigma reduction. People living with HIV should participate in these programmes as trainers.
  6. Health service providers and advocates should support closer linkages between HIV prevention, care, and treatment; comprehensive sexual and reproductive health services; drug substitution therapy; mental health and psychosocial services; and anti-discrimination and anti-violence initiatives.
  7. Advocates should ensure that special centres and programmes are developed to deliver information and services to hard-to-reach populations.
  8. Governments, international agencies, and NGOs, in collaboration with organizations of young people living with HIV, should develop specific guidelines for counselling, support and care for people born with HIV as they move into adolescence and adulthood.
  9. Governments, international agencies, and NGOs should better research and monitor the sexual and reproductive health of people living with HIV, including data disaggregated by gender, age, marital status, geographic location and sexual orientation. This research should be conducted with the input and supervision of people living with HIV.
  10. Governments, international agencies, and NGOs should set and monitor concrete targets for involving people living with HIV in all relevant activities, including positive prevention programmes.
  11. Governments, international agencies, and NGOs should support income-generating programmes. This includes directly employing people living with HIV, and paying them for their work.
  12. Advocates should ensure that programmes to bolster participation of people living with HIV also help build needed skills. In particular, women and young people should be provided with ‘know your rights/laws’ education and advocacy training.



## 2

# CREATING A SUPPORTIVE HEALTH SYSTEM

Much ill health and death around the world occur out of a lack of HIV and AIDS-related and reproductive health services. Health systems worldwide are facing significant challenges, which can make it hard to deliver even the most basic services to their populations. However, making the changes that would serve the sexual and reproductive health needs of people living with HIV could also make an important contribution toward resolving these overarching health systems challenges by improving public health overall.



The term 'health systems' describes all the organisations, institutions, and resources that a society devotes to improving, maintaining, or restoring health. This includes staff, funds, information, supplies, transport, and communications. Health systems encompass specific health clinics and interventions, as well as the larger infrastructure that

supports them. Robust health systems are critical to ensuring that people are able to get the care they need.

Many low-income countries have weak health systems simply because not enough resources – financial or human – are invested in this sector. In addition to these resources, a strong health system depends on a structure of policies and regulations to ensure that resources are used effectively and fairly. This structure includes, for example, referral programmes and the integration of related services; lists of essential medications and commodities; non-discrimination policies and complaint/recourse mechanisms; training programmes for health providers, including in informed consent and confidentiality; mechanisms for getting health services to marginalised group who frequently are hard to reach; support for and regulation of private, religious, or traditional providers of health services; and the research and monitoring of health outcomes.

Within the broad framework of health systems, support for the sexual and reproductive health of people living with HIV involves a package of specific services. Some of these are driven by needs that people living with HIV share with their HIV-negative counterparts, such as condoms to prevent transmission of HIV and other STIs. People living with HIV may also need additional services, such as those for preventing parent-to-child transmission of the virus. In general, health services that assist people living with HIV to attain and maintain sexual and reproductive health include the diagnosis, management, and treatment of HIV and STIs; sex education and information; psychosocial support to cope with living with HIV; family planning; services for safe abortion in circumstances where it is not against the law and post-abortion care; services to assist conception; antenatal and postnatal care; safe delivery services; cancer diagnosis and treatment; services to address gender- and sexuality-based violence; counselling and treatment to address sexual dysfunction; and HIV prevention.

People living with HIV have a right to accessible, affordable, appropriate services in order to protect and maintain their sexual and reproductive health and that of their sexual partners. Improved public health depends on making such services available. This chapter outlines the measures that should be taken to reform health systems in order to make this happen. The first section explores some of the current gaps and barriers within health systems, from inadequate or inefficient financing to failure to set health targets and monitor outcomes. The second section outlines the types of



## HEALTH SYSTEMS RECOMMENDATIONS

- Donor governments should increase funding to fill existing shortfalls, blending general budget support with targeted projects in politically sensitive areas.
- Governments should fund health care through public funding or insurance programmes rather than user fees.
- Through integration or referrals, health services should create a comprehensive continuum of care, from youth to adulthood to old age, that links HIV prevention, care, and treatment; comprehensive sexual and reproductive health services, drug substitution therapy, psychosocial and legal services, and anti-violence initiatives.
- Health systems should have formal linkages with community systems by and through which health system outcomes are monitored to ensure that these are positive outcomes and to ensure referral to other support systems, for instance in the social or legal spheres.
- Essential medicines lists should be reviewed regularly to ensure they include sexual and reproductive health commodities.
- Patient tracking systems (sometimes known as ‘case management systems’) should be established to ensure that people who are tested are referred to and can access treatment, care, and support.
- Donor governments and international agencies should help train and support health care workers in developing countries.
- Health workers should receive training in human rights and universal precautions, as well as specific training in sexual and reproductive health care for people living with HIV including technical skills, confidentiality, informed consent, non-discrimination, gender equality, and stigma reduction. People living with HIV should participate in these programmes as trainers.
- Pharmacists, traditional birth attendants, healers, and others in the informal health sector should be provided with education and support in meeting the sexual and reproductive health needs of people living with HIV.
- Advocates should ensure that special centres and programmes are developed to deliver information and services to hard-to-reach populations.
- Voluntary and confidential HIV testing and counselling should be made available to all, including migrants, prisoners, and other marginalised groups.
- Pregnant women being tested for HIV must receive prevention, treatment, care, and support services in addition to programmes to prevent parent-to-child transmission.
- Systems for prevention, treatment, care, and support must be strengthened to deal with increased demand at the same time that HIV testing is scaled up, to ensure that HIV testing – based on the ‘three C’s’ – results in referral to HIV prevention, treatment, care and support programmes.
- All people living with HIV – including members of marginalised groups, such as sex workers, people who use drugs, prisoners, refugees, and members of the lesbian, gay, bisexual, transgender and intersex communities – should have access to a full range of sexual and reproductive health services, including:
  - All available contraceptive options and help with dual protection, without coercion toward any particular method;
  - Access to safe abortion (in circumstances where it is not against the law) and post-abortion care;
  - Counselling and support for safe ways to become pregnant;
  - Counselling and practical support for infant feeding, whether breastfeeding or replacement feeding;
  - Counselling and practical support for positive prevention;
  - Diagnosis and treatment of STIs;
  - Cancer prevention and care;
  - Counselling related to violence;
  - Sexual dysfunction treatment; and
  - Male circumcision for men living with HIV if, when fully informed, they want the procedure.
- Positive prevention programmes must respect and support the rights of people living with HIV.

services that should be made available to meet the sexual and reproductive health needs and rights of people living with HIV and provides suggestions as to how these services should be structured.

## I. Structural Issues

Efforts to meet the sexual and reproductive health needs of people living with HIV are hampered by gaps in policy, funding, and training specific to sexual and reproductive health, as well as by the general weakness of health systems. Improving the health care infrastructure is critical to achieving sexual and reproductive health for people living with HIV. To strengthen health systems, both donors and low-income country governments must reform their practices.

### Financing

Most low-income governments rely on bilateral and multilateral donors to support medical care, particularly care for people in poor and marginalised groups. Over the last decade, international financial support for sexual and reproductive health services has grown, in part because of an increase in funding for HIV and AIDS interventions. Nonetheless, the United Nations estimates that in 2007 alone, the world fell US\$8 billion short of funds needed to provide universal access to comprehensive HIV and AIDS services.<sup>8</sup>

To better support the sexual and reproductive health of people living with HIV, **donors should increase their total amounts of funding, and make it easier for recipient governments to provide comprehensive, integrated services.** Much funding for HIV and AIDS is channelled through disease-specific mechanisms such as The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) or the United States' President's Emergency Plan for AIDS Relief (PEPFAR)<sup>9</sup> programme. Neither currently has a specific focus on the sexual and reproductive health of people living with HIV, while PEPFAR specifically excludes funding for some reproductive health services such as contraceptives.<sup>10</sup>

Some bilateral donors have begun to use Sector Wide Approaches (SWAs) and Poverty Reduction Strategies (PRS), which channel funds through general budget support mechanisms aimed at strengthening health systems. The Global Fund, too, is paying increasing attention to its role in

health system strengthening.<sup>11</sup> This approach eliminates the need for separate planning and reporting mechanisms for each donor-supported project, and should enable recipient countries to devote a greater proportion of resources to health care rather than donor reporting. Because these funds are not specifically linked to the provision of any particular package of services, though, it will be important to monitor service delivery to ensure that sexual and reproductive health concerns, in particular those related to people living with HIV, are not ignored. **Where possible, support should be provided to networks of people living with HIV,** who can provide this oversight function and generally help ensure continued civil society input into government spending priorities and programming.

Other bilateral support has been project-specific, sometimes financing politically sensitive programmes such as work with men who have sex with men, sex workers, or people who use drugs. Although project-specific support can complicate planning and reporting at the national level, it may continue to be a useful mechanism for financing sexual and reproductive health services for certain groups of people living with HIV who are not well served by mainstream HIV programmes or the broader health system.

Many governments also finance health care systems by collecting user fees for services. This can lead some people – particularly those who are poor – to avoid care or to postpone it until they reach more advanced stages of illness. User fees can be a serious problem for people living with HIV, particularly if they are unable to work because of illness or discrimination. Gender inequalities make user fees particularly problematic for women, who may lack resources of their own and need to seek funds from a male relative. **Pooling the financial costs of health care, through public funding or insurance programmes is a better way for governments to support disadvantaged groups and advance public health.**

### Linking services

Currently, sexual and reproductive health and HIV services are often provided through separate, parallel structures. In many places the Office of the President or Prime Minister manages HIV funds, while sexual and reproductive health funding is channelled through the Ministry of Health or the Ministry of Finance. Separate institutions procure commodities; develop

regulatory frameworks, drug lists, training manuals, and technical guidelines; and establish monitoring and evaluation mechanisms, with little interdepartmental consultation.

One way to ensure that people living with HIV have adequate access to sexual and reproductive health care is to link or integrate services. This could mean that clients obtain HIV services and sexual and reproductive health at a single site, or simply that health care workers have the knowledge and skills to provide an appropriate basic package of services and to refer patients for other necessary care that is not provided at that site.

New coordinating bodies and approaches may be necessary to ensure attention to the sexual and reproductive health of people living with HIV. 'Dual champions' in national agencies can work to build support and ownership for work in this area: For example, Ghana's presidential advisor on HIV and AIDS is a sexual and reproductive health expert and the chair of Nigeria's National AIDS Committee also has a reproductive health background – expertise which may increase their openness to addressing linkages between the two areas.

Linking services also means providing a continuum of care for patients across their lifespan, from birth through childhood, adolescence, adulthood, and old age. This is particularly important for people born HIV-positive. In the context of the sexual and reproductive health of people living with HIV, comprehensive, continuous care means **creating or strengthening connections between paediatric, adolescent and adult care; among HIV prevention, treatment, care, and support services; between pre- and post-natal care; drug substitution programmes; and to STI services, contraception, cancer prevention and care, and psychosocial services** for all clients, including young people and members of lesbian, gay, bisexual, transgender and intersex communities.

Providing sexual and reproductive health services to men and involving men in conception services, contraception services, and programmes to prevent parent-to-child transmission of HIV are also important considerations in service integration. Because women have been the primary clients at reproductive health clinics, men may be uncomfortable going to these sites. Programme managers may need to consider integration in both directions, incorporating sexual and reproductive health care into HIV services and vice versa.

Without adequate planning to ensure the addition of necessary human and financial resources, the integrating of services that were previously established as distinct, vertically organised institutions risks taxing health systems in resource-constrained settings. This burden may be exacerbated where responsibility for providing health services has been decentralised resulting in the parallel administration of vertical systems occurs across many districts and localities. Integration of programmes must be negotiated and implemented district by district. Local managers will need funding and training support, programme guidelines, and opportunities to learn from one another if they are to successfully broaden the scope of their services by linking or integrating related areas of care.

### Supplies and technologies

In a well-functioning health system, medicines and other health products – including sexual and reproductive health commodities – are available when needed. To make this happen, governments need to identify commodities, purchase them in adequate quantities, and develop effective systems to ensure that products meet quality standards and arrive in good condition at local clinics across the country. It is particularly important to ensure that a full range of sexual and reproductive health commodities – including lubricants, and male and female condoms – are available to people living with HIV.

One important tool for making appropriate commodities available is the essential medicines list, which helps ensure that available resources are devoted to prevent and treat the health conditions that most affect each country's population. However, these lists often neglect sexual and reproductive health commodities. For example, only one-third of countries include condoms on their lists.<sup>12</sup> WHO recommends that countries **review essential medicines lists yearly, which provides a regular opportunity to include necessary sexual and reproductive health and HIV and AIDS supplies and commodities.** To ensure the lists are appropriate and comprehensive, specialists in the sexual and reproductive



health of people living with HIV – preferably, people who are themselves living with HIV – should be represented on the committees that oversee the lists.

It is also important that those procuring and prescribing commodities know that the essential medicines list exists and understand how to use it in their work. Health care worker training should include instruction on essential medicine lists alongside treatment guidelines. When the lists are changed, these changes must be communicated to workers at the clinic level and accompanied by relevant training to support appropriate prescribing and treatment practices.

### Health care workers

WHO estimates a current worldwide shortfall of some 4.3 million health care workers; a combination of factors contributes to this shortfall including low or unpaid salaries and poor training, supervision, and working conditions.<sup>13</sup> This severe shortage of skilled workers seriously hampers the expansion of comprehensive services for people living with HIV.

WHO recommends that donors dedicate a quarter of all new health funding to training and sustaining the health workforce. Donors can help build a larger pool of health care workers by providing **financial support and technical assistance for health training institutions in countries facing severe health care worker shortages**. In addition, since a large part of the health care worker problem faced by low-income

countries is the exodus of trained staff to better-paid jobs in high-income countries and international agencies, governments should **develop and enforce policies on ethical recruitment of migrant health care workers**.

Once trained, health care workers also need more resources and better working conditions.

Workers may be unable to offer some sexual and reproductive health services to people living with HIV because they lack basic health commodities. Care can also be constrained by lack of infrastructure; for example, health care workers may be unable

to undertake home visits because there is no hospital transport available, or they may be unable or unwilling to provide services because they have only low-quality equipment (or none at all), lack electricity, or clean water. These frustrations drive some qualified workers away from providing health care, and limit others to providing sub-standard services.

To effectively address the sexual and reproductive needs of people living with HIV, health care workers need specific knowledge and skills. Many providers admit having problems dealing with people living with HIV, particularly those who report same sex behaviour, sex work, or injecting drug use.<sup>14</sup> Health care workers may need training and support to become more comfortable talking openly about sexuality, risk behaviour, and illicit drugs, and help understanding the critical importance of maintaining confidentiality. All health care workers should receive training in medical ethics and human rights, including non-discrimination, the duty to treat, the critical importance of maintaining confidentiality, and informed consent. There should be established and enforced professional codes of conduct which explicitly include references to such standards including with regards to people living with HIV. They should also be trained in national and international guidelines and protocols on HIV and sexual and reproductive health. Involving people living with HIV in such trainings has been shown to be particularly effective in overcoming misperceptions and stigmatising attitudes, and providing health workers with thorough and accurate information on their clients' needs.<sup>15</sup>

Finally, health care workers are themselves in need of HIV and sexual and reproductive health services. In countries with high HIV prevalence, HIV-related illness and death has a significant impact on the size of the health care workforce and the ability of health care professionals to work. Whilst one might assume that health care workers have easy access to services, many do not seek assistance because they fear the attitudes and reactions of colleagues and patients. A lack of privacy and confidentiality compounds this fear. To help protect their health, health care workers should be offered ongoing HIV prevention education, HIV testing and counselling, measures to assist health care workers living with HIV to continue working, priority access to antiretroviral therapy, improved systems to ensure the confidentiality of their HIV status with regard to both colleagues and patients, and workplace stigma reduction programmes.<sup>16</sup>



## HIV Stigma and discrimination

Although the occupational risk of HIV infection is low, health care workers and staff may resist providing services to people living with HIV out of fear of infection. Some workers perceive procedures like Intra-Uterine Device (IUD) insertion, vaginal examination, delivery, and examination of ulcerative STIs to be very risky, even with gloves on. To protect workers and reassure them that they can provide services safely, it is important to provide accurate information, training in universal precautions against infection, and the appropriate resources.

More broadly, HIV-related stigma and discrimination lead health care providers to treat people with HIV as beyond help or undeserving of services. They sometimes deny labour assistance to pregnant women with HIV, test pregnant women and people suspected of risk behaviours without consent, give test results to family members rather than to people with HIV themselves, otherwise violate privacy and confidentiality, pressure HIV-positive women to undergo sterilisation or abortion, or fail to inform women living with HIV about all their options regarding contraceptives or infant feeding.

As a result, even where sexual and reproductive health services for people with HIV exist, stigma and discrimination reduce the quality of these services and discourage people with HIV from using them. **Health care worker training should be expanded to raise awareness of existing legislation, policy guidance and professional standards on human rights and patient care, including with regards to duty to treat, non-discrimination, informed consent, and protection of confidentiality. Such trainings should address discriminatory attitudes towards people living with HIV, affirm the right of everyone to comprehensive and quality care, and provide precise information on how the virus is transmitted to address the fear of physical contact with patients. People living with HIV should participate in these trainings, which will also help reduce stigma by allowing health workers to interact personally with people with HIV. People living with HIV and other community members can also be enlisted to ensure that professional standards are met, and to speak out against violations.**

## Non-state actors: community organisations and informal health workers

Outside the formal health sector, an array of private organisations and individuals are involved in providing health care, assessing the quality and appropriateness of public health services, and ensuring government accountability. In some countries, traditional and informal health workers provide a significant amount of care, especially in the case of stigmatised health conditions such as unwanted pregnancies or STIs. **Better utilisation and remuneration of these traditional and informal health workers** could help improve services for the sexual and reproductive health of people living with HIV.

Collaborative initiatives between traditional and formal health care workers on HIV prevention, education, and counselling have encouraged traditional providers to offer accurate information on how HIV is transmitted, support prevention efforts by promoting and distributing condoms, and train people to recognise symptoms of HIV-related conditions.<sup>17</sup> Traditional birth attendants, in particular, can help implement HIV interventions with pregnant women: In Kenya, for example, traditional birth attendants are being trained to promote therapies to prevent parent-to-child transmission of HIV, recognise high-risk pregnancy complications in women with HIV, and accompany women with complications to clinics for treatment.<sup>18</sup> Similarly, pharmacy workers should be trained to recognise symptoms of STIs and provide appropriate counselling and referrals as well as treatment.

Community and faith-based groups provide a vast amount of medical services. Approximately one in five organisations delivering AIDS programmes is faith-based.<sup>19</sup> Community level work is also essential to addressing discrimination, poverty, low literacy, gender inequality, and lack of health information; all of which impede the ability of the health sector to address the sexual and reproductive health needs of people living with HIV. Governments and donors should acknowledge and support the critical role these groups play in households and communities in relation to health, health systems and beyond.

Finally, people living with HIV provide a great deal of care, education, and counselling to their peers. This work should be recognized and remunerated. HIV-positive people's groups and networks require adequate funding, as well as



training in sexual and reproductive health vis-à-vis both their services and advocacy. It is also vital that these groups are supported to access to antiretroviral therapy and treatment for opportunistic infections, not only for the health of their members but to enable their continued support for the health system and the community more broadly.

### Reaching marginalised populations

Certain groups of people living with HIV are unlikely to be reached by services offered in traditional clinics and hospitals. Some people – including sex workers, migrants, young people, drug users, prisoners, refugees, men who have sex with men, and lesbian, gay, bisexual, transgender and



intersex persons – may avoid services because they fear discrimination or even prosecution, or may be physically unable to access services. To reach marginalised and criminalised groups with sexual and reproductive health care and HIV testing, treatment, care, and support, health systems may need to **set**

**up special centres and**

**organise outreach activities.** Involving these communities in programme design and monitoring is the best way to ensure that services are appropriate, welcoming, and effective.

### Monitoring and evaluation

Policymakers and programme officials often lack data: Basic information on sexual behaviour and demographic information about many marginalised groups may be unavailable. This makes it difficult to locate and provide services to these groups, or to determine the extent to which they are being served or remain underserved. Better data is required to guide policies and programmes, both in terms of the numbers of people in need and being served, and the quality and effectiveness of services being provided. National governments must also establish ways to monitor their reach and effectiveness of policies and programmes are put in place to address the sexual and reproductive health of people living with HIV.

Determining what constitutes the ‘right data’ requires the input and active engagement of people most affected by the

epidemic. Existing indicators used by many national HIV programmes emphasise the breadth of coverage rather than whether programmes are effectively preventing and treating HIV or improving lives through care and support service. Few HIV programmes consider sexual and reproductive health (beyond condom use and the number of sites providing prevention of parent-to-child transmission services) as a measure of success; and, to date, there are no commonly agreed indicators to monitor and evaluate sexual and reproductive health care for people living with HIV, nor systems to support and evaluate continuity of care (e.g., linkages between HIV testing and counselling, and other HIV and sexual and reproductive health-related services). In light of the difficulty and resource-intensiveness of collecting and analysing data, it may not be productive to demand new indicators. Instead, existing indicators, such those set to monitor universal access to comprehensive prevention, treatment and care for HIV and AIDS by 2010, the Millennium Development Goals, and the progress of Global Fund and bilaterally-funded projects, could be further disaggregated by sex, age, sero-status and affiliation with a specific key population group to better measure – and thus to enable attention to – the sexual and reproductive health of all people living with HIV. Such efforts should be accompanied by community monitoring of the availability, accessibility (including non-discrimination), acceptability and quality of programmes and services.<sup>20</sup>

## II. Clinical Services

People living with HIV need specific clinical services. These services must recognize the diversity of needs among people living with HIV, including young people, people who use drugs, men who have sex with men, older people, people in prison, refugees, migrants and the internally displaced, and sex workers. Women also have needs not shared by men. In addition, gender cuts across all these populations and must be considered: female prisoners, migrants, and sex workers, for example, have different experiences and priorities than their male counterparts. Improving the availability and quality of services for each of these groups’ promises to improve the sexual and reproductive health of people living with HIV as well as those who are HIV-negative.

## HIV testing and counselling

Knowing one's HIV status – accompanied by appropriate counselling and support – helps people protect themselves and others from STIs, conceive and give birth safely, and obtain appropriate treatment and care. Currently, however, the vast majority of people with HIV do not know their HIV status. **HIV testing needs to be expanded, but with careful attention to ensuring that it is voluntary, confidential, and accompanied by quality counselling.** Before undergoing an HIV test, clients need information about treatment, care, and support, as well as help preparing for a possible positive diagnosis.

Health systems offer voluntary HIV testing and counselling under different models in a variety of settings. One model is voluntary counselling and testing (VCT), which has a significant advantage in that it is likely to be voluntary because the client initiates the test. Young people and men may prefer testing at standalone VCT clinics, while some adults, especially women, may find it more convenient to obtain VCT within the same medical facilities they already use for other services. VCT may also be available at home: While this may expand access to testing, there are also concerns that more powerful family members may force others to test. **Home-based VCT, like that offered in health facilities, should always be accompanied by counselling so that those testing positive are supported to understand the results and access care, treatment, and support services.**

Health care providers may also recommend testing to their clients as a standard component of medical care.<sup>21</sup> Provider-initiated testing and counselling may be either 'opt-in,' where clients must affirmatively agree to the test after they have received relevant information, or 'opt-out,' where the test will be provided unless the client specifically declines it. **Where the opt-out model of provider-initiated testing is used, it is important to ensure that clients understand that they have the right to refuse a test without repercussions.** Broadening the sites for testing beyond sexual and reproductive health facilities, where tests are most often offered, may help in reaching men and people outside their reproductive years.

Pregnant women are generally offered HIV testing and counselling on a routine basis as part of prenatal care. Because receiving an HIV-positive diagnosis during pregnancy or delivery may be traumatic, health care providers should give special attention to providing pre-test information that

includes the risks of transmitting HIV to the infant; measures that can be taken to reduce mother-to-child transmission, including antiretroviral prophylaxis and infant feeding counselling; and the benefits to infants of early diagnosis of HIV. Appropriate post-test counselling should be provided in the case of an HIV-positive diagnosis. All testing and counselling should be performed under conditions of informed consent and confidentiality. When undergoing HIV testing and counselling, **pregnant women must not be seen exclusively in their roles as mothers-to-be, nor should testing be used solely to prevent parent-to-child transmission. Prevention, treatment, and care services should always be available when testing is offered.**

In determining how and where to provide HIV testing and counselling services, health systems should take account of the special needs of marginalised groups who may face barriers in accessing health services. For example, people who sell sex may avoid HIV testing because they anticipate discrimination by health care workers or fear that disclosing their occupation may put them at risk of arrest or prevent them from continuing to work. When sex workers do visit testing sites, they may need special services, such as counselling on how to access confidential HIV and other health services, how to access social support programmes for themselves and their dependants, alternative livelihood options and whether/how to change occupation, and laws and legal services that may protect sex workers who face violence or discrimination.

Financial and logistical barriers can prevent women – particularly rural women who may have to travel long distances to reach clinical services – from accessing HIV testing and counselling. In other cases, women may avoid testing because they fear abandonment or violence from male sexual partners. Guarantees of confidentiality and supportive counselling are particularly important for women, as family members and partners may pressure women to test and then blame them for 'bringing HIV into the home' if they test positive.

Adolescents and young people, too, have a special need for confidential tests and supportive counselling. Health systems should work to address the barriers that keep young people from testing, such as requirements that parents know about the test and/or test results.<sup>22</sup> Counsellors should find ways to help young people decide whether and how to disclose their

status. Parents and other family members can be an enormous support to positive young people, but disclosure may also prompt anger, fear, violence, or abandonment of the young person with HIV. Young people may also be unable to pay for tests, so health systems should work to provide free or low-cost testing. These issues are of particular concern for young women, who make up the majority of young people living with HIV are female: in Sub-Saharan Africa, for example, three-quarters of young people living with HIV are young women. Further complicating matters, many of the young people most vulnerable to HIV and AIDS – such as, street children, injecting drug users, and sex workers – are also the most marginalised and hardest to reach, so health systems need to reach out beyond standard clinics and hospitals.

HIV testing and counselling programmes may also overlook older people, as few sexual and reproductive health services are explicitly aimed at them. Further, health care workers sometimes mistake the symptoms of HIV in older people for

age-related conditions. Sexual and reproductive health facilities and other testing settings should be sensitive to HIV in older people and target this group in outreach activities.

Confidentiality of HIV status is particularly important within prisons and other closed settings. Prisoners should not be quarantined, or offered

visibly preferential treatment that singles them out as living with HIV. Prisoners living with HIV also need post-test services for healthy living with HIV, including prevention counselling and access to antiretroviral treatment. Ongoing counselling following the completion of prison sentences is important to help support continuity of care and access to services. Such counselling should also take into account other psycho-social needs.

### Sex education

Many people diagnosed with HIV report that they did not fully understand that their sexual behaviour put them at risk of infection. Good quality education on sexual health and HIV

helps people avoid unintended pregnancy, STIs, and HIV, and mitigates stigma and discrimination against people with HIV.<sup>23</sup>

Women and men living with HIV need information on how to choose appropriate methods of contraception, the links between STIs and HIV infection, the risk of re-infection, the effect of HIV on menstruation and fertility, and safer ways of conceiving, having a healthy pregnancy, and giving birth.

Health providers should be sensitive to their clients' emotional needs and provide sex education at times and in ways that it can be best absorbed. Particularly when providing HIV test results, it is critical to address people's anxieties and concerns before giving factual information. It is also important to go beyond simply providing facts, with continuing counselling support on practicing safer sexual behaviour and maintaining safe behaviour over time.

In many countries, older community members – sometimes through initiation ceremonies and rituals – have traditionally conducted sex education with girls and boys. With changing social structures, urban migration, and the separation of families, young people may no longer benefit from these channels of information. Reinvigorating traditional channels of communication may help young people obtain sexuality information and relationship skills. Studies suggest that initiators would be willing to update their ceremonies in the light of HIV to provide accurate and relevant support to young people.<sup>24</sup>

Outreach and peer education programmes can reach particularly vulnerable groups such as adolescents, sex workers, men who have sex with men, and people who inject drugs. These programmes work best when members of vulnerable groups are themselves involved in designing and delivering appropriate educational messages.

Within prisons, HIV is transmitted through illegal or stigmatised behaviours, such as sex between men and injecting drug use. Many men and women also enter prison already HIV-positive. Prisoners need ongoing, non-judgmental, and accurate information on protecting and caring for themselves, delivered through materials that are relevant to the realities of the prison environment.

In all settings, sex education and HIV counselling should be adapted with the needs of the key audience in mind. Refugees,





migrant workers, and internally displaced people may need specialised materials that provide information about HIV and sexual and reproductive health in their own languages and in culturally appropriate formats.

### **Psychosocial support**

People living with HIV need psychological and social support to make informed decisions about their health and to tackle stigma and discrimination. From a sexual and reproductive health perspective, such support might address pressure from families and communities to have, or not to have, children; violence and fear of violence; rights violations such as widow inheritance; negotiation of safer sex; and worries around disclosure of HIV status to partners, family members, and the wider community. Yet programmes rarely address these needs effectively, because psychosocial support is often seen as a ‘soft’ and low-priority service, or because health care workers lack the training and support they need to provide unbiased, non-judgmental advice.

Within health facilities, psychosocial support should not end with post-test counselling for people diagnosed with HIV; it should be part of the ongoing patient and health care worker relationship. Psychosocial interventions may take place either in HIV service settings or in sexual and reproductive health-related clinics. Community and faith-based organisations may be able to meet psychosocial needs as well, particularly where there are not enough trained health care workers.

Peer support groups are an important way for people to come to terms with the implications of being HIV-positive: Support groups give people living with HIV the space to articulate their experiences, realise they are not alone, and share survival strategies. However, peer support groups sometimes fail to adequately address other forms of discrimination, such as those based upon age or gender. Peer educator training programmes and support groups should make a special effort to recruit members from disadvantaged groups and ensure that their voices are heard and respected.

Members of certain groups have particular psychosocial needs to which require awareness and sensitivity from counsellors. Young people with HIV may need extra support in dealing with their transition to adulthood and understanding the physical and emotional aspects of sexual relationships. They may also face difficult decisions about disclosing their status.

Young people living with HIV who have experienced violence or sexual abuse may need to be referred to specialist services. HIV-positive women may need specialist psychosocial help if they are making decisions around breastfeeding, if they learn their status whilst pregnant or deciding whether to become pregnant, if they are survivors of gender-based violence, or if they fear they will face violence and rejection when they disclose their status. Counsellors should also be aware that divorce, separation, and bereavement might lead older people living with HIV to embark on new sexual relationships, often without negotiation skills or safe sex education.

### **Family planning and dual protection**

People living with HIV may want to avoid pregnancy for a variety of reasons: They may fear that the child will become infected with HIV, already have the number of children they desire, want to avoid infection with another strain of HIV, or need to focus their resources on maintaining the health and wellbeing of themselves and their families. However, HIV-positive people often lack adequate access to family planning services, and may receive inaccurate information about their family planning options. They may also be forced to cope with community and family pressures to have children, partner opposition to contraceptive use, and stigma associated with condom use.

In many developing countries, the most commonly used contraceptive method is sterilisation. Many women living with HIV have experienced pressure from health care workers to undergo sterilisation, a violation of women’s reproductive rights: It is important to ensure that this option is discussed in a non-directive way and that informed consent is obtained. **Most contraceptive methods are considered to be safe and effective for women living with HIV**, although some antiretroviral medications may interact with some oral contraceptives, potentially affecting the effectiveness of either or both medications. Adjusting dosage, changing to another contraceptive, or using condoms can address this problem.<sup>25</sup>

Dual protection means the simultaneous prevention of unintended pregnancy and HIV and STI infection through the consistent and correct use of male or female condoms, alone or in combination with another contraceptive method. Reproductive health programmes have tended to steer their patients away from condoms toward other forms of contraception, in the belief that other methods are more

effective at preventing unintended pregnancies and because condoms were stigmatised through their association with disease prevention. Many people find it difficult to use condoms correctly and consistently every time they have sex: Women living with HIV can face particular difficulties in adopting dual protection because they lack the power to insist on condom use, and many people underestimate their vulnerability to HIV and STI infection because they falsely believe the sexual relationship they are in is monogamous.

A better integration of HIV and sexual and reproductive health services can help health workers advise clients on how to manage, reduce or eliminate all their sexual risks, including the risk of sexually contracting STIs as well as the risk of unintended pregnancy. Family planning services, including information about dual protection, are most obviously delivered through family planning clinics, but can also be incorporated into a range of other sites. Integrating family planning services and supplies into VCT services, for example, serves a dual purpose: It ensures that all patients, whether testing HIV-positive or not, have access to information and contraceptive commodities and it may attract clients to the VCT centre who would not otherwise have come. Currently, however, national VCT guidelines generally address family planning only in terms of counselling and referral, rather than as a fully integrated service.<sup>26</sup>

STI services tend to be aimed at particularly vulnerable groups such as sex workers and men who have sex with men. Because the objective of these services has been reducing STI and HIV prevalence, they have paid little attention to the family planning needs of either patients in general or clients living with HIV. However, given that they are already providing information and supplies related to condom use, STI clinics represent a potential opportunity to increase awareness and provide contraceptive services.

HIV treatment, care, and support services are another logical place to offer family planning advice and commodities to people with HIV. These services have identified the need to train personnel in family planning counselling, and some refer women to family planning services. In general, though, they are still struggling to meet the need for antiretroviral treatment and have not yet been able to prioritise family planning. One exception is programmes to prevent parent-to-child transmission of HIV, in which family planning is often

a key element. These interventions may also offer services to help protect prospective parents and children from HIV infection, safe delivery services, and postpartum advice and support for safe infant feeding.

Certain groups are particularly neglected by systems currently in place to provide family planning services. For example, programmes focused on HIV prevention, treatment, care, and support for men who have sex with men have overlooked the possibility that they have female partners with whom contraception may be important. Lesbians, too, have family planning and sex education needs. While sex between women is unlikely to result in HIV infection, some lesbians become HIV-positive through sex with men, sex work, injecting drug use or other causes, and their sexual and reproductive health should be addressed.

Programmes for sex workers have tended to concentrate on HIV prevention with their clients, rather than addressing women's relationships with their partners within which contraception may be a key concern. A recent study among sex workers in Cambodia found that the vast majority were relying on condoms alone for dual protection, with fewer than five percent using another modern contraceptive method.<sup>27</sup> Outreach programmes can help ensure that appropriate information and supplies reach everyone at risk.

## Abortion

Even where contraception is available, contraceptive failure, coerced and forced sex, inability to insist on contraceptive use, or changes in personal circumstances (such as bereavement or divorce) can result in an unwanted pregnancy. **Women with HIV should have access to services to prevent unsafe abortions, to safe abortion services in circumstances where it is not against the law, and to post-abortion care.** However, in many parts of the world, all women face significant barriers in seeking abortion-related care. Women living with HIV may face further difficulties in seeking abortion-related services due to added stigma and discrimination. In addition, health care workers may refuse to provide women living with HIV with abortion services due to fears about potential infection.

To ensure that women living with HIV have access to safe abortion-related care, every hospital and clinic should have staff trained to provide basic sexual and reproductive health services. Sites that are not equipped to provide induced abortions or post-

abortion care must refer women promptly to the nearest service. Health care staff should also be competent in providing accurate and non-directive counselling to allow women to consider their fertility options. WHO guidelines recommend the technique of vacuum aspiration when terminating a pregnancy in women living with HIV, and the routine use of antibiotics to reduce the risk of post-procedural infections.<sup>28</sup>

Preventing coerced abortions is a critical aspect of ensuring that women living with HIV have access to safe, appropriate abortion-related care. Women living with HIV in many parts of the world have reported such coercion: For example, in one study in Asia more than two-thirds of women testing positive whilst pregnant reported they were advised not to have children, and nearly one-quarter reported being coerced into sterilisation or an abortion.<sup>29</sup> Health care workers should be trained to provide women living with HIV with comprehensive counselling and services so women can make informed decisions based on their own health and personal situations.

### Conception, pregnancy and childbirth

Giving birth and motherhood play a significant role in the social status and self-identity of women in many cultures. As access to antiretroviral therapy increases and HIV can be experienced as a chronic rather than a fatal disease, people living with HIV are more likely to desire children. However, physical and psychosocial difficulties, compounded by negative attitudes among health care providers who do not believe that people with HIV can or should have children, can make conceiving and bearing children difficult.

People living with HIV may have more difficulty becoming pregnant than HIV-negative couples. Studies have reported that fertility of HIV-positive women is lower than that of HIV-negative women in all but the youngest age group.<sup>30</sup> Men living with HIV may also experience reduced fertility. Health technologies do exist to address these problems, but services are rare, particularly in resource-poor settings.

**Safe conception methods differ depending on the sero-status of partners, and people living with HIV who are considering becoming pregnant should be counselled about these options:**

- When only the woman is HIV-positive, insemination with the partner's semen eliminates the risk of infection for the male partner.

- When the male partner is HIV-positive, there is no risk-free method to ensure safe conception. Lowering the viral load to undetectable levels with antiretroviral therapy, semen washing, and *in vitro* fertilisation can reduce the risk of transmission. Insemination by donor semen is another option.
- If both partners are HIV-positive, to limit risk of re-infection they should try to conceive at the time during the menstrual cycle when the woman is most fertile. Semen washing can also reduce the possibility of transmitting virus mutations.

Once a couple has successfully conceived, pregnancy does not appear to affect HIV progression. However, HIV can make pregnant women more susceptible to certain illnesses and poses some risks to the infant.<sup>31</sup> Health care workers should provide pregnant women living with HIV with insecticide-treated bed nets, tuberculosis treatment, and nutritional supplements, as appropriate. Women with HIV who are pregnant should receive all standard antenatal care services, including screening and treatment for STIs and nutritional counselling and monitoring. Antenatal care should also incorporate appropriate antiretroviral therapy, which keeps mothers healthy and helps protect the foetus from infection.

STI infection during pregnancy can cause serious complications for both mothers and babies, and a pregnant HIV-negative woman with a partner living with HIV also needs protection from HIV for herself and her unborn baby. Despite this, health workers rarely advocate the use of condoms during pregnancy, and women may find it especially difficult to ask their partners to practice safer sex during this period. Health professionals should work to reframe condoms in pregnancy as protection for the unborn baby as well as the mother, and as a sign of mutual caring and protection within the relationship, rather than one of distrust. It is also important to provide adequate supplies of condoms to make safe sex possible.



HIV-positive drug users who become pregnant need additional specific services. Opioid substitution therapy during pregnancy and following childbirth can help protect both women and their babies, and may encourage pregnant drug users to use other sexual and reproductive health services, including antenatal care.

Most women in developing countries give birth at home without skilled care, leaving them vulnerable in the event of an obstetric emergency. **Pregnant women with HIV need skilled health care providers who can perform caesarean sections if needed, administer antiretroviral therapy during labour, and abide by protocols specific to HIV-positive women.** After delivery, mothers should be monitored for post-partum infection, which generally requires more aggressive antibiotic treatment in women with HIV. Counselling on safer sex – including dual protection – is important as intercourse too soon after birth can lead to infection.

HIV-positive mothers need counselling and practical support for infant feeding, whether breastfeeding or replacement feeding. To prevent parent-to-child transmission of HIV, **health care workers should promote either exclusive breastfeeding or exclusive replacement feeding** (accompanied by adequate supplies of milk formula). Mixing breastfeeding with formula feeding significantly increases the risk of an infant becoming infected with HIV.<sup>32</sup>

Associations of people living with HIV can play a major role in postpartum counselling, especially regarding infant feeding strategies. Particular attention should be given to avoiding stigma and discrimination for women who choose not to breastfeed (in effect 'outing' themselves as HIV-positive in some communities). HIV-positive mothers need to know how to safely prepare replacement feeding, what they should do if babies have oral sores or they themselves have sores or inflammation around their nipples, and how to carry out abrupt weaning. They may also need financial support to purchase replacement feeding. Women who are mobile (e.g., refugees or migrant workers) may need extra support in continuing their chosen feeding method when they move.

### **Sexually transmitted infections**

The timely and appropriate diagnosis and treatment of STIs and reproductive tract infections is vital to ensuring the health of people with HIV. HIV can facilitate the transmission of STIs,

and tends to make them more aggressive and harder to treat. Because people sometimes learn they are HIV-positive at a VCT centre or during treatment of an opportunistic infection, rather than in a sexual and reproductive health setting, they do not always receive a full STI screening at the same time.

The easiest way for people with HIV to obtain STI screening and services is to incorporate these services at locations where they regularly go for clinical services, for example sites that provide antiretroviral therapy. Service providers should consider how best to **include regular sexual health check up as an integral component of routine HIV care.** Alternatively, clients can be referred to a separate, stand-alone STI clinic for these services. In this case, the two services will need to establish reliable communication policies to ensure that relevant information is shared in a timely and confidential manner to promote continuity of care.

In turn, STI clinics have important opportunities to diagnose HIV infections – especially in its early phase when HIV is most infectious – among patients who seek treatment for an STI. HIV testing and counselling should be routinely offered as part of STI services. Those who test positive should receive intensive counselling and support, while those who test negative should be strongly urged to use condoms consistently or abstain from sexual activity until they have a repeat HIV test within 6-12 weeks, as seroconverters may still be in the window period when antibodies are undetectable.

Special attention should be paid to the needs of prisoners, who may have contracted STIs outside of prison or via unprotected sex within prison. The presence of untreated STIs also increases the risk of HIV transmission, and vice versa. Prevention and regular screening and treatment of STIs improves prisoners' health overall and increases the effectiveness of HIV prevention and treatment efforts.

### **Cancer diagnosis and treatment**

People living with HIV are at increased risk for a number of cancers, particularly in resource-poor settings where many are not receiving antiretroviral therapy. In addition to the sexual and reproductive health-related cancers discussed here, providers should be alert to timely diagnosis and treatment of other AIDS-defining cancers such as Kaposi's sarcoma and non-Hodgkin's lymphoma, as well as breast cancer which is not AIDS-related but poses a risk to many women.

Cervical cancer is a serious complication of persistent infection with the human papillomavirus (HPV) – a STI that affects up to 80% of sexually active men and women. Compared with other women, women living with HIV have an increased prevalence of persistent HPV infection, an increased risk of precancer, and a faster progression to invasive disease.<sup>33</sup> WHO recommends **cervical cancer screening for all women at the time of HIV diagnosis**, and women living with HIV should have **regular pelvic examinations and HPV screening**. Health centres should be able to provide or refer for treatment of cervical lesions.

HPV is also the underlying cause of anal cancer. Anal HPV infection is widespread amongst men who have sex with men, particularly those with HIV, as well as to some extent among HIV-positive women. Some HIV clinics are exploring the value of regularly screening individuals with anal HPV for precancerous cells, using a test very similar to the Pap test used to detect pre-cancerous cervical cells in women.

Primary health care providers with minimal equipment and training can implement many cancer services, although laboratory support is required. In many countries elements of cancer care already exist within various sexual and reproductive health structures; what is needed is a coherent programme to link them to health care services for people living with HIV.

### Violence

People living with HIV are at particular risk of violence, and **screening for violence and referrals for health care and psychological and legal assistance need to be integrated into sexual and reproductive health services and HIV programmes**. Survivors of sexual assault need access to services including psychological care, STI diagnosis and treatment, emergency contraception, and abortion services where legal. Gender-based violence makes women and girls vulnerable to HIV infection in the first place, and perceived and actual threats of abuse may prevent women from using contraceptives and condoms or from accessing health care and counselling services. Women living with HIV are at even greater risk of violence, which can also result in unwanted pregnancies and prevent women from using VCT and health care services. In addition, social stigma and feelings of self-blame can discourage women who have experienced violence from using sexual and reproductive health services.

Men who have sex with men are often victims of violence, particularly in settings where homosexuality is illegal or highly stigmatised, and as with women, those living with HIV are at greater risk. Sexual violence increases risk of HIV infection and re-infection, both through physical injury such as ruptured rectum and internal haemorrhage. Violence and abuse can make men who have sex with men more likely to engage in high-risk behaviours, such as unprotected anal intercourse, substance abuse, and exchanging sex for money or drugs.

Particularly where homosexuality is criminalised, men who have sex with men may lack health and legal services to help them recover from and avoid abuse. Where criminalisation prevents general health services from addressing violence against men who have sex with men, stand-alone services are needed. These should include counselling as well as diagnosis and treatment of STIs.

### Sexual dysfunction

Men with HIV commonly report concerns around loss of libido and erectile and ejaculatory problems, some of these related to HIV itself and others to antiretroviral therapy or other medications. Men who have sex with men may experience loss of sexual desire due to external or internalised homophobia. Women living with HIV also experience sexual dysfunction. Underlying reasons may include post-diagnosis depression, anxiety, loss of self esteem, body changes or altered body image, fear of violence or trauma associated with past violence, the symptoms of STIs, change of roles in couple relationships, the death of a spouse or partner, social isolation, fear of re-infection, and fear of infecting others.

Loss of sexual drive or desire can have a significant impact on quality of life and feelings of self-worth, and may contribute to emotional problems such as anxiety and depression. Yet health programmes for people living with HIV often focus on preventing onward transmission of the virus, neglecting issues associated with a safe and satisfying sex life.





People living with HIV should be offered the same therapies for sexual dysfunction as people who are HIV-negative, such as medications to treat erectile dysfunction and lubricant, particularly for women following menopause. They may also benefit from specific approaches, such as switching drug regimens to address reduced desire due to side effects such as stomach pains, headaches, and lipodystrophy. Training for health workers who will be providing HIV and sexual and reproductive health services should include information on these therapies, as well as support in talking about sexual dysfunction and sexuality. Many people with HIV have found peer support groups to be helpful in combating isolation, fear, and lack of information around HIV, all of which can diminish sexual desire.

### Positive prevention

People who are HIV-positive need prevention programmes to help them stay healthy, avoid STIs and re-infection, and protect their partners from HIV infection. To be effective, positive prevention strategies must be responsive to and compatible with the practical realities people living with HIV face in trying to protect themselves and others. This requires that people living with HIV provide leadership in developing these strategies.



Positive prevention programmes must respect and support the rights and responsibilities of people living with HIV, including confidentiality, informed consent, and voluntary disclosure. They also need to address stigma and discrimination, both in the clinical setting and in the community. Positive prevention efforts that do

not confront stigma and discrimination and promote shared responsibility may discourage people from finding out their HIV status and changing their behaviour accordingly. Further, since only a small proportion of people living with HIV worldwide are aware of their status, positive prevention must place responsibility on everyone – not only those who know they are positive – to reduce transmission of HIV.

Positive prevention programmes must also address the structural, social, legal, and political constraints that undermine the efforts of people with HIV to protect and maintain their health and that of others. Those who disclose their status may risk rejection, discrimination, and violence. Restrictive laws and policies may limit their ability to access medical services. Cultural norms may prevent them from negotiating condom use with their sexual partners, even when condoms are freely available. Positive prevention efforts must empower groups of people living with HIV to reach out into the community and other decision-making arenas to help change these unhelpful norms and empower people living with HIV. ‘Know your rights’ campaigns and other training and engagement strategies are important components of supporting people living with HIV to demand HIV prevention – not only commodities and services, but the conditions of non-discrimination and freedom from violence that makes HIV prevention possible.

## III. Protecting Human Rights, Advancing Public Health

People living with HIV wish to have sex, bear children, prevent unwanted pregnancies, protect their sexual health and protect the health of their partners. Yet the stigma and discrimination that people living with HIV confront in all aspects of their lives is compounded by the fact that sexual and reproductive health policies, programmes, and services often fail to take into account their unique needs. To begin with, health systems in low-income countries simply lack the human and financial capacity to meet their people’s health needs. Specific gaps and weaknesses in policies, training and programmes further undermine the ability of health systems to support the sexual and reproductive health of people living with HIV.

Addressing these gaps, as outlined in this chapter, will help realise human rights and the sexual and reproductive health of people living with HIV while also reducing illness, slowing disease progression, and preventing onward transmission of the virus. Investments in health and community systems that will enable people living with HIV to better protect their own sexual and reproductive health and the health of their partners and children will also benefit HIV-negative men, women, and children, ultimately supporting everyone’s health.

### 3

## LEGAL AND POLICY CONSIDERATIONS

In most ways, people living with HIV have the same sexual and reproductive health-related needs and rights as anyone else. For example, everyone has the right to decide whether and when to have children, no one should be subject to medical interventions without their informed consent, and the results of everyone's medical tests and health status should be kept confidential. In many places, however, existing laws and policies fail to support the ability of people living with HIV to meet such needs and achieve their sexual and reproductive aspirations. Even worse, certain laws and policies severely constrict the sexual and reproductive rights of HIV-positive people.

National governments can improve the situation, first, by **enacting, implementing, and enforcing laws that prohibit discrimination against people living with HIV in both the public and private spheres**. Anti-discrimination laws help remove barriers that would otherwise make it difficult for people living with HIV to obtain sexual and reproductive health care, as well as employment, education, health insurance, housing, and other social benefits. Governments can also develop and implement national frameworks and guidelines that explicitly protect the sexual and reproductive health of people living with HIV.

Beyond this, there are numerous specific laws and policies, such as HIV testing protocols, residence requirements for

obtaining health services, or the criminalisation of certain sexual practices between consenting adults, that apply to the population generally but specifically affect the sexual and reproductive health of people living with HIV. Some of these policies will have implications for all or most people living with HIV, while others will affect people belonging to key population

groups facing health disparities within HIV epidemics. By reforming such laws and policies, governments can make great strides in enabling people living with HIV to get the information and services they need to protect their own health and the health of others.

Law and policy development or reform is most effective when the people directly affected by them are involved – not only in their formation, but also implementation, monitoring, and evaluation. People living with HIV (and particularly members of key populations) are in the best position to design effective interventions, highlight areas of concern, and ensure that legislation takes account of the larger social, policy, and legal context in which HIV-positive people live.

Improving laws and policies is a critical first step, but laws on paper do no good unless they are implemented. Globally, people living with HIV and supportive advocacy groups have established guidelines and tools to help decision-makers create policies that better support sexual and reproductive health, and to help advocates monitor progress. National-level mechanisms, such as national human rights institutions (e.g., an ombudsman or human rights commission) and national court systems, can help enforce legal obligations to protect sexual and reproductive health and address alleged violations of human rights. Where national level mechanisms are not in place or not effective, regional human rights commissions, such as those established in Africa and the Americas, may be helpful. Governments can also be pressured to fulfil obligations under the international human rights treaties they have ratified, for example through civil society 'shadow reports' to the international committees which monitor compliance. See the section on monitoring and evaluation below for further discussion.



Finally, it is essential that all people, including those living with HIV, have access to justice. This means that people living with HIV should benefit from programmes that educate them about their rights and the relevant laws in their countries. Programmes should also ensure that people living with HIV can access legal aid in many forms, whether it be legal aid to utilize the courts or make contracts, or access dispute resolution in the context of working through customary legal systems. Judges, lawyers and holders of customary and/or religious law should also be educated about the legal and social needs and rights of people living with HIV, including their sexual and reproductive health rights.

This chapter addresses common policies and laws that affect people living with HIV, particularly those pertaining to criminalisation of HIV transmission or of particular sexual behaviours such as anal sex, HIV testing and counselling,

mandatory disclosure requirements, family planning, marriage and childbearing, inheritance rights, and male circumcision. It outlines the sexual and reproductive health significance of each issue, highlights potential areas of concern related to different types of laws and policies, and refers to relevant international human rights guidelines. It particularly stresses the importance of including people living with HIV in the formulation and monitoring of these laws and policies. The chapter then discusses legal and policy issues relating to the sexual and reproductive health of key populations which have been disproportionately affected by HIV, including young people, women, sex workers, drug users, men who have sex with men, transgender people, prisoners, migrants, and refugees.

A human right to the highest attainable standard of health has been globally recognised; still, for many people around the

## LEGAL SYSTEMS RECOMMENDATIONS

- Anti-discrimination laws should include sexual orientation, gender identity, and health and HIV status, and explicitly cover key populations at greater risk.
- Non-disclosure of HIV status, HIV transmission, anal sex, sex work, same-sex relationships, and transgender relationships should be decriminalized.
- HIV testing should never be mandatory, and always be based on the ‘three Cs’: confidential, based on informed consent, and conducted with counselling. This applies equally to marginalized groups, including migrants, refugees, and prisoners.
- Women living with HIV should be provided with the full range of contraceptive options and should never be coerced into undergoing sterilisation or abortion.
- HIV status should not affect a person’s right to marry or found a family, should not be grounds for divorce, and should not be relevant in child custody decisions.
- Women’s property rights should be ensured and protected, particularly following a spouse’s or partner’s death, divorce or abandonment.
- Men living with HIV should be permitted to undergo circumcision if, when fully informed, they want the procedure.
- Governments, international agencies and NGOs should set and monitor concrete targets for involving people living with HIV in all relevant activities.
- Young people should have the right to access confidential medical services and should not need parental permission for sexual and reproductive health care, even if they are below the age of majority.
- Governments, international agencies and NGOs, in collaboration with organizations of young people living with HIV, should develop specific guidelines for counselling, support and care for people born with HIV as they move into adolescence and adulthood.
- Injecting drug users should be provided with treatment, including opioid substitution and harm reduction programs rather than incarceration.
- Transgender people should be legally recognized and clear procedures should be in place for changing name and sex on official documents.
- Health care in prisons should be under the responsibility of the health care system, not the prison system, with a view to promoting continuity of care as prisoners move back into the general community.



world, particularly people living with HIV, this right has yet to be supported by concrete policies and programmes. This chapter points the way toward realising the right to sexual and reproductive health for all.

## I. Sexual and Reproductive Health-Related Laws and Policies

Everyone has the right to the highest attainable standard of health,<sup>34</sup> and the primary aim of providing sexual and reproductive health services to people living with HIV should be to safeguard this right. Supporting the sexual and reproductive health needs of people living with HIV also has clear public health benefits, as it enables people with HIV to live healthier, more productive lives and to better protect others from infection. Despite this, the global response to the HIV epidemic has generally treated people living with HIV as vectors of disease rather than people with their own sexual and reproductive health needs and rights. At the same time, HIV-positive people have not been provided with the information, services, commodities and social support needed to effectively avoid passing the virus on to others. This section highlights some of the problems with this approach and suggests more effective policy directions.

### Criminalisation of HIV transmission

In some places, transmitting HIV to another person is a criminal offence. Enacting HIV-specific laws may give the impression that parliamentarians and policymakers are taking 'strong measures against HIV' and those placing people at risk of HIV infection. This is particularly true in countries where many women are being infected by husbands or regular sexual partners. However, **relying on criminal law to prevent HIV transmission is counterproductive.**

The possible negative implications of overly broad criminalisation of HIV transmission is significant.<sup>35</sup> Such laws fail to send the message that **everyone** needs to take measures to protect themselves from communicable diseases, which can undermine public health campaigns designed to encourage everyone to practice safer sex and avoid infection. Nor do these laws help people living with HIV to disclose their status to their partner(s) without fear of negative consequences or access HIV prevention services.

While some people *may* be deterred from having risky sex, or sharing needles and syringes, because they fear criminal penalties, almost certainly the fear of criminal penalties will do more to deter those most at risk from getting tested for HIV: If a person has not been tested and does not know their status, in principle they cannot be charged with 'knowingly' transmitting the virus. Without seeking testing and counselling, there is no opportunity for information and support towards changing behaviours that risk HIV transmission or to access treatment or care and support services. One may even be reluctant to seek treatment for STIs – which if left untreated increase the risk of HIV transmission.

Criminalising high-risk sexual and drug injecting behaviours among people living with HIV can make it even more difficult to provide effective education about preventing HIV infection. It may undermine trust between people living with HIV and their counsellors, if they fear that information revealed in counselling sessions may be turned over to law enforcement authorities. In addition, criminalisation of HIV transmission may deter a pregnant woman living with HIV from seeking antiretroviral treatment or prenatal care, out of fear of prosecution if her child is born HIV-positive.

If criminal law is used in this context, it should be limited to the exceptional circumstances of intentional transmission (where someone deliberately sets out to infect another and does in fact do so), and in the context of general criminal law provisions rather than new, HIV-specific legislation.

### Anal sex

Criminalising consensual sexual behaviour between adults is as counterproductive as criminalising HIV transmission. Nevertheless, many countries have criminalised anal sex. National laws should be reformed in accordance with international guidelines to ensure that criminal laws prohibiting sexual acts between consenting adults in private are repealed. Where such laws exist, individuals should not be denied health services on the basis of their actual or supposed sexual activities.

Studies show that as many as a third or more of heterosexual couples, and a larger proportion of men who have sex with men, have engaged in anal sex.<sup>36</sup> HIV is transmitted much more easily through anal than vaginal intercourse. However, women and men may be reluctant to talk about it with

partners or health care providers because anal sex is subject to taboo, stigma, denial, and homophobia. Criminalization of anal sex only exacerbates the stigma associated with the practice and makes it even more difficult for people who engage in anal sex to seek HIV prevention, treatment, or care.

### HIV testing and counselling

The overwhelming majority of people living with HIV do not know they are HIV-positive, and so they do not receive treatment, care, and support in a timely manner and may not take steps to prevent transmission to others. Efforts are certainly needed to expand HIV testing and counselling. However, **policies should be in place to ensure that testing is voluntary and confidential, and that it includes appropriate pre- and post-test counselling, as well as access to treatment, care, and support.**



It is critical to ensure that health service providers do not disclose the HIV status of any of their clients without the client's fully informed consent. HIV-positive people should be supported to disclose their HIV status, but they must be able to decide how and when to do this. It is also important to ensure that those who have been tested have access to

adequate prevention, treatment, care, and support services. Policymakers should keep in mind that expanded testing programmes are likely to expand the demand for treatment, as well as other forms of care and support, and ensure that the capacity to meet this demand is in place.

Certain groups in some countries have been forced to undergo mandatory HIV testing. Targets of mandatory testing have included migrants, refugees, or travellers; military personnel; pregnant women; children who are being adopted or subject to custody/access orders; couples intending to marry; people seeking insurance; hospital patients, including patients of mental health facilities; prisoners and others held in closed settings; people with developmental or severe physical disabilities; injecting drug users; men who have sex with

men; and employees, especially in certain occupations such as health-care workers, pilots, some religious orders, entertainers, sex workers, truck drivers, and fishermen. UNAIDS and WHO both oppose mandatory HIV testing, which violates human rights with no demonstrable public health benefit. The International Guidelines on HIV/AIDS and Human Rights state that public health, criminal and anti-discrimination legislation should prohibit mandatory HIV testing of targeted groups, including vulnerable populations.<sup>37</sup>

### Family planning and abortion

At the International AIDS Conference in Barcelona in 2002, nongovernmental organisations (NGOs) helped to formulate the Barcelona Bill of Rights of women living with HIV, which includes the rights to contraception, safe pregnancy, and safe termination of pregnancy. Many advocacy organisations followed by issuing statements that emphasised the right of girls and women to bear and not bear children. The bottom line of most of these documents is that HIV-positive women should have the same access to reproductive health services as their HIV-negative peers, and be entitled to make the same choices.

To plan their families, women living with HIV have the same need for contraception that all women do. All family planning methods, including hormonal contraceptives and emergency contraception, are good options for HIV-positive women.<sup>38</sup> In some cases, however, antiretroviral therapy programmes have required women to use particular, provider-defined contraceptive methods in order to be eligible for treatment. Policies should be established to **ensure that women living with HIV, including those taking antiretroviral medications, retain the right to make their own informed decisions about contraceptive use.**

Any contraceptive method can fail, and some women with unintended pregnancies decide not to carry their pregnancies to term. An HIV diagnosis can prompt some pregnant women to want to seek an abortion.<sup>39</sup> However, many countries have laws that prohibit or restrict access to safe abortion: An estimated 26 percent of people reside in countries where abortion is generally prohibited.<sup>40</sup> A few countries with restrictive laws have exceptions that permit HIV-positive women to terminate their pregnancies on the basis of their HIV status. Some countries allow legal abortions to be performed to protect a woman's health, and under these policies women living with HIV may be eligible for abortion services.

In countries where safe abortion is legal and available, it remains unclear whether pregnant HIV-positive women receive complete and unbiased counselling to enable them to make a fully informed decision, including information about abortion and the risks of pregnancy and delivery to the health of both the woman and the foetus, as well as prevention of parent-to-child transmission. In South Africa, for instance, providers are not required to discuss abortion as an option for HIV-positive women facing unwanted pregnancies. The opposite problem also occurs, with numerous reports of pregnant women living with HIV being pressured or coerced into having unwanted abortions.<sup>41</sup> Women living with HIV should be counselled on all reproductive options available to them. If HIV infection is explicitly considered grounds for legal abortion, it is important to ensure that pregnant women are informed and counselled about such an option, but never pressured into undergoing an abortion simply because they are HIV-positive.

In some countries women living with HIV have been pressured into undergoing sterilisation. **Forced sterilisation or abortion should be specifically outlawed, and policies should ensure that women living with HIV have comprehensive and accurate information about, and access to, all the family planning options generally available, the right to choose abortion where it is legal, and access to post-abortion care.**

### **Marriage, divorce, and child custody**

Entering into marriage and childbearing are internationally recognised human rights.<sup>42</sup> **People living with HIV should not face any restrictions on their right to marry or have children.**

In some places, laws require couples to test negative for HIV before they are allowed to marry, effectively denying people living with HIV the right to marry, even though means exist to protect HIV-negative partners from infection. A partner's HIV diagnosis has been considered grounds for divorce in some jurisdictions. Such laws and practices simply add to the stigma surrounding an HIV diagnosis, discourage people from seeking HIV testing and counselling and from disclosing a positive test result to a spouse – thus making it more likely the infection will be transmitted.

People living with HIV have been denied custody of their children following separation or divorce, despite the fact that people living with HIV can lead full productive lives and be

active, supportive parents.

The Convention on the Rights of the Child (Article 9) stipulates that the overriding criterion concerning decisions about separating a child from his or her parents is 'the best interests of the child'. **A parent's HIV status should be irrelevant to child custody decisions, and family laws should ensure that the parental rights of people living with HIV are protected.**

Same-sex couples and transgender people face particular barriers to marriage and family, whether or not they are HIV-positive. Although many transgender people marry, the legality of those marriages is not always clear and is subject to national interpretation (e.g., when one partner in a heterosexual marriage legally changes their sex during the marriage). It is important to establish legal guidelines that ensure that all people, regardless of sexual orientation or gender identity, have equal partnership rights. Particularly for people living with HIV, basic partnership rights can be critically important – such as the right to make financial and health care decisions for the other person in the event that they become incapacitated, or the right to survivor's benefits in the event of death.

### **Women's property and inheritance rights**

Women whose partners fall sick and die may suffer discrimination, abandonment, and violence. Women who are suspected of being HIV-positive face these same problems. Widows are frequently barred from inheriting property, meaning they may be evicted from their lands and homes and stripped of their possessions by in-laws. In some countries, a widowed woman is treated as property to be inherited by the male relative of the dead husband, which not only prevents her from inheriting any property of her own, but can also result in further HIV transmission if either of them is HIV-positive. Thrust into precarious economic situations, widowed women may be forced into risk-taking behaviour merely to provide basic needs such as food, shelter, and clothing for themselves and their children.



Policies that **ensure that women retain ownership and control over land and economic assets** will support them to achieve an adequate standard of living for themselves and their families, and can help empower them to negotiate abstinence, fidelity, and safer sex, and to avoid exchanging sex for money, food, or shelter. Beyond specifically ensuring that widowed women retain rights to their marital home and are not forced into marriage with other family members, policymakers can support the property rights of women, including married women, more generally. These include the right to own property, enter into contracts, obtain credit, and bring litigation. Such policies can help support widowed women living with HIV to care for themselves and their children, avoid risky behaviours and exposure to STIs and unwanted pregnancies, and seek out health services.

### Male circumcision

Studies have shown that under clinical trial conditions, male circumcision can reduce the risk of HIV-negative men becoming infected with HIV by their HIV-positive female partners during vaginal intercourse by up to 60%; however, male circumcision has not been shown to offer any protection for HIV-negative women nor HIV-positive women and men.<sup>43</sup> UNAIDS and WHO recommend that countries expand access to male circumcision services as part of comprehensive HIV prevention programming; however, they stress the importance of developing a regulatory framework to ensure these services are delivered safely and ethically.<sup>44 45</sup>

Taking a human rights-based approach to the development or expansion of male circumcision services means ensuring that the procedure can be carried out safely, under conditions of informed consent, and without coercion or discrimination. Policies should be in place to ensure that all men opting for male circumcision receive full information on its benefits and risks. **Men living with HIV should be permitted to undergo the procedure (unless it is medically contraindicated), although they should be informed that there is no evidence that the procedure will protect their partners from infection.** Male circumcision may provide a valuable opportunity to offer HIV testing and counselling. However, HIV testing should not be a pre-condition for accessing services; mandatory testing runs counter to human rights standards and may discourage men from seeking circumcision.

Where male circumcision is provided for HIV-positive minors (young boys and adolescents), the child should be involved in decision-making and given the opportunity to provide consent, to the extent he is capable depending on his age. Parents who are responsible for providing consent should be given sufficient information regarding the benefits and risks of the procedure in order to determine what is in the best interests of the child.

### The greater involvement of people living with HIV

Broadly, to ensure that laws and policies support the sexual and reproductive health and human rights of people living with HIV, it is essential that people living with HIV play a genuine role in decision-making. Since its formal adoption at the 1994 Paris AIDS Summit, the principle of the Greater Involvement of People Living with HIV (the GIPA principle) has been widely accepted. The personal experience of living with HIV provides an invaluable expertise and unique perspective on the real-world impact of abstract policies.

To ensure the practical implementation of the GIPA principle, **governments and international agencies should set and monitor concrete targets for the participation of people living with HIV in the choice, design, implementation, monitoring, and evaluation of sexual and reproductive health-related policies.** These targets should specifically address the inclusion of marginalised groups (including women and young people), to ensure that a broad range of voices and experiences are represented.

## II. Policies Affecting Key Populations At Higher Risk

Certain groups of people living with HIV face exceptional legal and policy barriers to getting the sexual and reproductive health services they need. Many individuals belong to more than one of these marginalised groups (for example, a man who sells sex to other men and injects drugs, or a transgender sex worker, or an adolescent migrant), which multiplies their barriers to care.

### Young people

Some 5.4 million people worldwide between the ages of 15 and 24 are living with HIV. Because young people are more likely to seek care in a safe, welcoming environment free from



potentially judgmental adults, policies should seek to promote youth-friendly clinics and services as much as possible. Schools and other public institutions should also provide protective environments and policies for young people living with HIV.

Sexual health education for all young people, including those living with HIV, must be comprehensive, accurate and age appropriate, and include information on family planning, the dangers of early pregnancy, and HIV and STI prevention, symptoms, and management. Policymakers should ensure that national guidelines and curricula are in place towards these ends, and that teachers are trained to deliver the curricula and respond to questions that young people have.

Confidentiality is a critical issue for young people living with HIV. They need to know that their HIV status will remain private, and may need support in deciding how to disclose their status to families and partners. Where there are legal requirements that a parent or guardian provides consent for a young person to access sexual and reproductive health services, such laws and policies must be changed as they can seriously restrict a young person's access to services. Similarly, the disclosure of test results or sexual and reproductive health concerns to parents will deter young people from seeking assistance and testing. Following any reform of law and policy towards greater protection of young people's right to confidentiality and right to access services, it is important that health care providers receive adequate training and understand their duty to protect young people's right to confidentiality.

Many countries regulate the minimum age at which people can consent to sex and the age at which they can marry. It is important that **adolescents are permitted to get sexual and reproductive health services, even if they are below the age of consent for sex.**

New vaccines against the human papillomavirus (HPV) have the potential to protect both men and women against reproductive cancers, as long as they are administered before a person has been exposed to a high-risk strain of HPV. As countries develop ways to deliver the vaccines, they should ensure that programmes are accessible and affordable, target young men as well as young women, and do not deny the vaccine to those who are living with HIV.

In general, national frameworks and curricula need to do more to address the sexual and reproductive health concerns of young people who are already living with HIV, including forming relationships, practicing safe, pleasurable sex, and disclosing their status. Existing programmes tend to ignore the needs of young people who have been HIV-positive since birth, largely because until recently HIV-infected infants were not expected to survive to adolescence. **Guidelines should be revised to specifically address the situation of young people who were born HIV-positive**, as well as those who were infected at a later stage.

### **Sex workers**

Sex work takes places all over the world and can be legal, regulated, or illegal. HIV prevalence is usually higher among sex workers than in the general population. However, few sex workers receive adequate HIV prevention, treatment, care, and support services. Further, the programmes that do address HIV and sex work often focus on reducing risk by ending sex work, rather than empowering sex workers, including those who are HIV-positive, to protect and care for their own health.

Where sex work is illegal, sex workers may avoid health services, including sexual and reproductive health care and HIV care and treatment, for fear that their name, HIV status, and other personal information will be made available to the police or other government agencies. Depending on whether outreach programmes exist, sex workers may lack information concerning where to go for treatment of HIV and other STIs, the skills to negotiate with their clients, or an adequate supply of condoms. Sex workers may also have difficulty obtaining health care because they are excluded from employment-based public health care insurance or entitlement systems. Further, when sex workers do seek services, they may find that health workers are unsympathetic to their needs. Where the law limits or prosecutes involvement in sex work, it is important to ensure that sex workers' rights



to HIV-related and sexual and reproductive health services, information, and education remain intact.

Sex workers experience severe levels of violence from sexual partners and the community. More than 90% of female sex workers in Phnom Penh, for example, report that they have been raped in the past year.<sup>46</sup> The illegal status of sex work often makes it more difficult to punish perpetrators of violence. HIV and sexual and reproductive health programmes for female sex workers should integrate services to lessen the likelihood and effects of violence. These may include work with local police and community leaders to improve attitudes towards sex workers, and legal services to support women who wish to speak out against abuses perpetrated against them.

Some countries have attempted to reduce HIV transmission through policies that prevent people living with HIV from selling sex. Such laws may simply discourage sex workers who suspect they may be HIV-positive from getting tested, or from seeking health services at all. Rather than penalizing people living with HIV, programmes should provide sex workers with confidential and voluntary HIV testing and treatment, STI prevention and management, male and female condoms, and contraceptive services. Where sex work is illegal, policies should include special provisions for sex workers who have been trafficked or coerced into sex work. People who have been coerced should not be prosecuted; they should, however, be referred to appropriate counselling, care, and support, including HIV services.

### Drug users

Worldwide, an estimated 13 million people inject drugs, while millions more use non-injected drugs. Needle sharing

among injecting drug users accounts for some 5-10% of HIV infections globally.

People who use drugs of any kind also tend to be more likely than non-users to take sexual risks. The sexual and reproductive health needs of drug users, particularly those who are HIV-positive, should not be overlooked.



Using drugs is highly stigmatised both within the general community and among health care workers. This means that health care services, including HIV treatment and sexual and reproductive health care, may not be available to drug users. Drug users may also be unable or unwilling to seek out services for fear of recrimination or incarceration.

As an alternative to prosecuting, some countries officially register drug users, particularly pregnant women who inject drugs and are seeking maternal and health care services. Because the registered person may be barred from working in certain forms of employment, receiving a driver's license, or being eligible for state-supported housing or other benefits, such 'alternatives' also act as a significant barrier to seeking care. **Treatment programmes are more likely than either incarceration or registration to encourage people who use drugs to seek and receive health services, as well as to end or better manage drug use.**

Harm reduction programmes such as sterile needle and syringe exchange programmes have proven effective for the prevention of HIV and other blood-borne infections, and are considered an international 'best practice' in HIV prevention. Some governments have adopted ordinances to allow anonymous needle exchanges and supervised injecting sites. When expanded HIV prevention services are made available at such sites, drug users can better access sexual and reproductive health services without fear of arrest. The benefits of harm reduction programmes increase considerably when they go beyond syringe exchange alone to include HIV education, counselling, and referral to treatment options. When expanded to include this wider range of services, harm reduction programmes also help people living with HIV to obtain treatment and protect themselves from STIs and unintended pregnancies.

Similarly, substitution maintenance therapy for opioid dependence can be embedded in a larger programmes offering sexual and reproductive health services and HIV-related information and counselling. Substitution therapy can be provided on an out-patient basis, which encourages people to remain in programmes longer and use related services to tackle health, psychological, family, housing, employment, financial, and legal issues. Such programmes offer important opportunities to scale up HIV prevention and improve the

delivery of antiretroviral therapy to drug users who are living with HIV.

### Men who have sex with men

Sex between men occurs in every culture and society, though it is not always publicly acknowledged. Men who have sex with men can be at increased risk of HIV infection if they have multiple sex partners, use condoms irregularly, or inject drugs. Unprotected anal sex carries a very high risk of HIV infection. While statistics are incomplete and vary widely from country to country, at least 5–10% of HIV infections worldwide are estimated to occur through sex between men.<sup>47</sup>

All people are entitled to the full protection of their human rights, regardless of their sexual orientation or gender identity. In March 2007, international human rights experts released the Yogyakarta Principles<sup>48</sup>, which specifically apply existing international human rights law to issues of sexual orientation and gender identity. These Principles stress the human right to decide freely and responsibly on matters regarding sexuality, including sexual and reproductive health, free from coercion, discrimination and violence. Sexual and reproductive health is acknowledged as a fundamental aspect of the right to the highest attainable standard of physical and mental health.

In many countries, though, sexuality is a taboo subject and sex between men is socially disapproved of, legally prohibited, or criminalised. As a result, health workers and employers discriminate against men who have sex with men, and police may harass or arrest them or those trying to provide them with HIV and STI services. Furthermore, men who have sex with men may conceal their sexual behaviours and medical symptoms from health care providers, with the result that STIs go undiagnosed and untreated. Such difficulties are exacerbated for men living with HIV, who must overcome the joint stigma of HIV infection and same-sex relationships. Even where sex between men is not itself criminalised, countries may outlaw specific types of consensual sexual behaviour (such as anal sex), which in effect criminalises many men who have sex with men and discourages them from seeking services. Laws may also designate different ages of sexual consent for heterosexual and same-sex relations, which implies that same-sex relations are not 'normal'. Such laws can also dissuade men who have sex with men from seeking services or from communicating openly with health workers.

To remove barriers to accessing needed health services, **the use of criminal law to regulate sexual acts between consenting adults in private should be avoided.**

### Transgender People

Transgender people often face increased risk of HIV infection, for reasons that include having multiple sex partners, using condoms irregularly, injecting drugs and/or hormones, and engaging in sex work. However, they have largely been ignored in HIV prevention, treatment, care, and support efforts, despite having repeatedly asked for services tailored to their needs. Transgender people may have difficulty getting HIV treatment, care, and support because they are low-income, lack health insurance, or are afraid to reveal they are transgender. Even when they attempt to obtain services, transgender people may be verbally harassed and mistreated, overtly excluded from programmes, or encounter health workers who do not know how to provide appropriate care.

The pervasive stigmatisation of transgender people greatly exacerbates their risk of HIV infection and diminishes their ability to obtain HIV-related care and treatment. Stigmatisation results in social marginalisation, which includes the denial of educational, employment, and housing opportunities. Such marginalisation lowers self-esteem, increases the likelihood of drug use and survival sex work, and lessens the likelihood of adopting safer sex and injecting practices. Stigma and marginalisation also create direct barriers to obtaining health care, including sexual and reproductive health services and HIV-related treatment, care, and support.

The legal status of transgender people varies from country to country. Few countries have laws recognising transgender people or protecting them from discrimination.<sup>49</sup> Because this lack of recognition leaves transgender people, in effect, legally invisible, governments largely ignore their needs – including HIV-related and sexual and reproductive health needs. To improve access to services, **governments should move to legally recognise transgender people in their own right.**

Another confusion is the designation of sex on legal documents (such as driving licenses and birth certificates) and medical records. In some countries, a change of legal sex designation may only proceed after genital surgery for male-to-female transgender people or chest reconstruction and

hysterectomy for female-to-male transgender people. Further, a legal change is often impossible for people who are married (because same-sex marriage is illegal in most countries). As surgery is not available in most countries and is not desired by many transgender people, and because many transgender people are married, many people who have fully transitioned still have a legal sex that does not match their gender identity or appearance. As a result, transgender people may be reluctant to show identification, which can prevent them from accessing services, including health care.

Many people who transition change their names to better match their gender identity or expression. A legal name change is an expensive and labour-intensive process, involving changes to all records and identification. During this process, different agencies may have different names on record, creating further problems in relation to accessing services. **Simplifying the procedures for changing name and sex could make it much easier for transgender people, particularly those living with HIV, to get the sexual and reproductive health care they need.**

### Prisoners

Nearly ten million people are held in penal institutions throughout the world. HIV infection is widespread in the world's prison systems, with prevalence well above national

rates. Prisons also usually have higher prevalence of other diseases such as hepatitis B and C, syphilis, and tuberculosis, and prisoners are often co-infected with two or more of these diseases.

Many prisoners belong to groups already vulnerable to HIV, such as injecting drug users, men who have sex with men, sex workers, and

migrants. Many prisoners are young. Some may be infected before incarceration; others become so while incarcerated through risky activities such as injecting drug use, tattooing, and unprotected sex. The vast majority of prisoners are released back into their communities at some point; therefore,

providing those who are HIV-positive with treatment, care, and support will also protect the wider community.

Lack of resources and the low priority of prison budgets is a serious challenge to the health, including sexual and reproductive health, of prisoners. HIV initiatives face added hurdles because prison system officials and staff and policy-makers may deny sex between men occurs in their prisons or oppose measures such as condom distribution that seem to condone illegal and 'immoral' behaviour. In Malawi, for example, when the NGO Banja la Mtsogolo worked to educate prisoners and treat them for STIs, some prison officials refused to accept that sexual activities were taking place and prohibited condom distribution.<sup>50</sup> Education of officials may be an essential first step in any intervention.

Another problem for the provision of health services in prisons is that it often falls under the responsibility of the prison service, rather than under the national health infrastructure that provides care to non-prisoners. **It is more likely that prisoners will receive the same access to health care that is available outside of prison – including HIV treatment and care, treatment for opportunistic infections, STI management, and vaccination against hepatitis A and B and HPV – when the Ministry of Health oversees their care.**

### Migrants

Some 191 million people worldwide are migrants living in foreign countries, in addition to hundreds of millions of people who have migrated within their own countries.<sup>51</sup> Increasing labour demands and widening disparities between countries encourage people to move to wealthier countries to improve their prospects, whether seasonally, for more extended periods, or permanently. Some are able to make such a move legally, and others migrate illegally.

HIV prevalence is often elevated among migrant communities. Migration, for example, has been identified as a significant factor in the rapid spread of HIV in Southern Africa. Providing migrants with better HIV prevention, care, and treatment, as well as sexual and reproductive health care more generally, would have broad public health benefits for the receiving communities as well as among migrants themselves. However, these needs are generally not on government agendas.





Instead, migrants are treated as a threat to public health. In the case of migrants living with HIV, many governments have focused first on exclusion. Travel and immigration restrictions often require people to prove they are HIV-negative before entering or remaining in a country. Testing under such circumstances is akin to mandatory testing, and in many instances it is done without appropriate pre- and post-test counselling or safeguards to maintain confidentiality. An HIV-positive test result means that the person is excluded from entry or deported.<sup>52</sup>

Besides being discriminatory, entry, stay and residence restrictions lack public health justification. Education and support to promote behavioural change have proven more effective and lasting than restrictive measures – which may deter nationals and non-nationals alike from coming forward to utilise HIV prevention, treatment, care, and support services. Restrictions against migrants living with HIV may create the misleading public impression that HIV is a ‘foreign’ problem that can be controlled through measures such as border controls, rather than through sound public health education and other prevention methods.

There is no evidence to suggest that blanket HIV-specific restrictions on entry, stay and residence have an economic justification.<sup>53</sup> With increased access to antiretroviral therapy, people living with HIV are now leading long and productive working lives. Concerns about migrants as a ‘drain on health resources’ must be weighed with their potential contribution to a society. In such assessments, HIV should be considered as any other health condition. Australia and Canada, for example, apply such health criteria in assessing whether to provide admission for HIV-positive immigrants.

However, even if a HIV-positive migrant enters a country legally, his or her access to health care may be severely restricted. In many countries, health care is tied to employment or citizenship. Many people who migrate undertake low-paying domestic or service sector jobs that citizens of the host country are unwilling to do; generally such jobs do not include health care insurance or other entitlements, and few low-paid migrants can afford to pay for health services on their own. Difficulties in obtaining care are exacerbated for those who have entered a country illegally.

### **Refugees and internally displaced people**

At the end of 2006, there were nearly 10 million refugees worldwide. Uprooted from homes, communities and social networks to escape conflict, persecution or violence; losing their means of livelihood; lacking access to quality health care; disrupting education; and in many cases subject to sexual violence and exploitation, refugees are at increased risk for multiple sexual and reproductive health problems including HIV infection. The majority of refugees live within host communities, not in camps, and many are displaced for extended periods of time. As a result, failure to address their HIV-related needs not only denies refugees their rights, it also undermines efforts to address HIV among host communities.

Yet refugees are overlooked in the HIV National Strategic Plans of many host countries. Refugees often lack access to HIV prevention commodities and programmes or basic HIV-related care and support. Despite improvements in the availability of antiretroviral therapy, far too few refugees living with HIV are receiving treatment. High levels of sexual violence in camps for refugees and displaced persons and the resulting risk of HIV infection could be partially addressed by ensuring that female residents have safe access to food, fuel, water, and other camp services.

In some countries, governments mandate HIV testing of refugees and internally displaced persons in the mistaken belief that this will help prevent HIV transmission. As among the general population, HIV testing among refugees should be voluntary and confidential, accompanied by counselling, and provided with access to the best care, and treatment options available.

## **III. Linking Legal Reforms to Sexual and Reproductive Health**

National laws and policies could be reformed in many ways to better support the sexual and reproductive health of people living with HIV. Some of these directly involve sexual and reproductive health services (for example, ensuring that young people can access these services without parental consent, if necessary), while others improve sexual and reproductive health by fostering a more supportive environment in other areas (for example, ensuring that women living with HIV can inherit their husbands’ property).

It is equally important to ensure that beneficial policies are actually implemented on the ground. International and regional agreements can provide guidelines and in some cases means of individual recourse when human rights standards are violated.<sup>54</sup> At the national level, national human rights institutions (e.g., an Ombudsman or Human Rights Commission) can work to monitoring implementation and enforcement of legislation. The courts may also be able to enforce legal obligations to protect sexual and reproductive health and rights.<sup>55</sup>

experience satisfying, fulfilling and healthy sex lives, safely bear healthy children, reduce unintended pregnancies, and minimise the transmission of STIs, including HIV.



Governments also need to better understand the size and specific needs of key populations, particularly groups at increased risk of HIV who are often marginalised and hard to find. Existing national surveys and HIV epidemiological surveillance systems should collect data on the sexual and reproductive health of groups including young people, sex workers, men who have sex with men,

transgender people, and people who use drugs. Governments and donors should also support epidemiological, social, and behavioural research for and by these groups.

All efforts to develop laws and policies in this area must be undertaken with the full involvement of people living with HIV, including members of marginalised groups. Organisations of people living with HIV have already taken the lead in developing tools and methodologies to monitor progress. For example, GNP+, ICW, IPPF and UNAIDS have developed a People living with HIV Stigma Index and methodology.<sup>56</sup> The Global Coalition on Women and AIDS, IPPF, UNFPA and Young Positives have produced report cards to strengthen HIV prevention strategies for girls and young women<sup>57</sup>, and the International Treatment Preparedness Coalition has published a series of assessments of how well countries are prepared to scale up antiretroviral therapy<sup>58</sup>.

Together with stronger, more supportive health and community systems, and robust, skilled advocacy efforts, legal and policy reforms can enable people living with HIV to

## 4

# EFFECTIVE ADVOCACY

People living with HIV have been talking about sex and reproduction from the beginning of the epidemic. HIV and AIDS forced gay men to redefine their sexuality and incorporate condom use to protect themselves and their partners from HIV and other STIs. From North America to Australia, they successfully articulated 'safer sex' messages within peer education campaigns. Organisations of women living with HIV have broadened the discussion to include issues and choices related to reproduction, including contraception, fertility, pregnancy, abortion, birthing, and breastfeeding.

Programmes and policies, however, have been slow to address the full spectrum of sexual and reproductive health and human rights issues connected with vulnerability to HIV, the impact of AIDS, and the overall well-being of people living with and affected by HIV. To be effective, the needs and rights of people living with HIV must be at the centre of all policy and programmatic efforts.

Early in the epidemic the focus was on preventing HIV, particularly among 'vulnerable groups' of people, sometimes without acknowledging that people with increased vulnerability to HIV infection generally have the same sexual and reproductive needs and desires as anyone else. In 1996, triple combination antiretroviral therapy was proven to be effective in reducing viral load and disease progression;

advocacy efforts, followed by programmes, began to focus on providing treatment.

Improvements in access to antiretroviral therapy were, and continue to be, driven by the efforts of people living with HIV. Advocates spoke out clearly and persistently for treatment access as a human rights issue. They also showed that treatment assists prevention efforts; people are more willing to undergo testing if treatment is available, and treatment lowers viral loads which may decrease the likelihood of infecting others. These powerful arguments led to international efforts including the WHO's '3 by 5' initiative, the United States' PEPFAR programme, and the Collaborative Fund for HIV Treatment Preparedness.

However, most global efforts to increase access to treatment have not addressed sexual and reproductive health and rights. Some early work has occurred in this area. ICW has been a pioneering voice, conducting research since 2000 on the sexual and reproductive lives of women living with HIV and using their findings as the focus of advocacy work. In 2005, WHO, IPPF, UNAIDS, and UNFPA produced a framework for priority linkages in sexual and reproductive health and HIV. In 2006, EngenderHealth, in conjunction with Harvard University, ICW, Ipas, and UNFPA, conducted an electronic forum on sexual and reproductive health issues. EngenderHealth and ICW have since developed a training manual that addresses HIV and sexual and reproductive health for women and girls.

Doing more to support the sexual and reproductive health and rights of people living with HIV will require concrete policy and programme changes in many areas, including sex education, HIV counselling and testing, family planning, pregnancy and birth services, marriage, and systems for the diagnosis and treatment of STIs, reproductive cancers, and sexual dysfunction. Specific recommendations for next steps in these areas were laid out in Chapters Two and Three of this Guidance Package. Promoting these recommendations will, in large part, drive the advocacy agenda in this area.



However, there is also advocacy work to be done apart from legal reform and improving the delivery of health services. Advocates must fight stigma and discrimination against people living with HIV, patriarchal attitudes toward women and young people, the marginalisation of many groups of people most vulnerable to HIV, persistent poverty, and a lack of coordination and collaboration. This chapter will explore these challenges and point to ways which activists and NGOs can work to overcome them. It will then suggest some ways to improve the ability of sexual and reproductive health organisations and networks of people living with HIV to advocate for sexual and reproductive health and rights, so that their efforts result in action. More information on the specific resources and tools mentioned throughout the chapter is available in the Appendix.

## I. Challenges To Effective Advocacy

To realise the sexual and reproductive health and rights of people living with HIV, advocates will have to overcome a number of barriers. In many cases, the same factors that make people vulnerable to HIV infection also undermine their ability to engage in any sort of advocacy work, and specifically make it difficult to discuss sexuality and reproduction. Advocacy organisations should work both externally and internally to foster an environment where people living with HIV have the freedom and the capacity to advocate for their sexual and reproductive health and rights, as this section will describe.

### ADVOCACY RECOMMENDATIONS

- People living with HIV should be trained and engaged in community education programmes to overcome stigma.
- Sexual violence should be recognised and prosecuted as a crime.
- Men and boys should be involved in programmes to stop gender-based violence.
- Advocates should ensure that programmes to bolster participation of people living with HIV also help build needed skills. In particular, women and young people should be provided with advocacy training.
- Advocates for people living with HIV should partner with other groups, including those advocating for the rights of sex workers, people who use drugs, men who have sex with men, transgender people, migrants, ethnic minorities, refugees, and prisoners.
- Governments, international agencies and NGOs should support income-generating programmes, in particular by directly employing people living with HIV and paying them for their work.
- People living with HIV should conduct their own sexual and reproductive health-related research and should have substantive input into the research of others. Specific areas needing additional medical or social research include:
  - The effects of antiretroviral therapies on HIV-positive young people’s physiological development, including sexual and reproductive health;
  - The sexual and reproductive health rights and needs of transgender people who are HIV-positive;
  - Documentation of laws criminalizing HIV transmission and anal sex, and implications for access to HIV prevention, treatment, care and support;
  - Documentation of discrimination against men who have sex with men in healthcare facilities;
  - Documentation of discrimination against women living with HIV in sexual and reproductive health centres and other facilities offering similar services; and
  - The risks and benefits of male circumcision for men living with HIV, and their male or female partners.
- Advocates should use tools to monitor adherence to the Declaration of Commitment on HIV/AIDS and international human rights treaties and provide shadow reports to relevant monitoring bodies.
- People living with HIV should form alliances and partnerships with government institutions, health and other professional organisations, associations of lawyers and judicial officials, and national human rights institutions to advocate for greater attention to sexual and reproductive health and human rights, within and beyond the national AIDS response.

## HIV stigma and discrimination

HIV-related stigma and discrimination is entrenched in society. Stigma and discrimination affects sexual and reproductive health among people living with HIV: for example, health workers, thinking that an HIV-positive diagnosis should mean an end to sex, may fail to provide people living with HIV with appropriate information on sexual and reproductive health; and, more broadly, fear of stigma may lead people living with HIV to avoid health services or to conceal sexual activity from health workers, so they lose out on appropriate information and care.

Stigma also stops people diagnosed with HIV from joining organisations of people living with HIV or becoming involved in HIV-related activism, as many people fear disclosing their status publicly. Those who are open about their status may be discriminated against within networks and organisations focused on human rights or sexual and reproductive health. As a result, they may not even be aware of their sexual and reproductive rights, or may not have a platform from which to insist on these rights.

People living with HIV will be even less prepared to engage in advocacy activities when they fear public exposure will lead to their arrest. Laws that criminalise same-sex relationships, sex work, or drug use not only make it more difficult for vulnerable people to access information and care, they also make people reluctant to get involved in HIV-related activism for fear of disclosure.

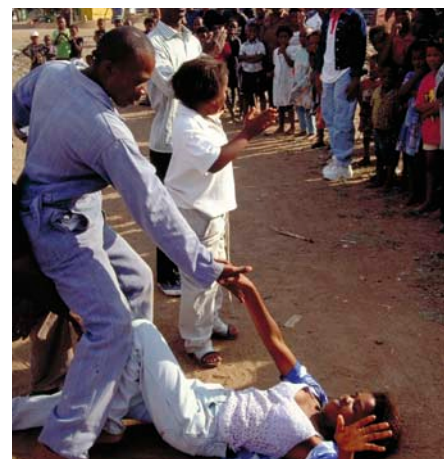
Community education is one important way that local and international NGOs can work to overcome stigma and discrimination. Better information and understanding around HIV, sex, and drug use can help overcome the fear and blame that lead community and family members to discriminate against people living with HIV. In particular, **HIV-positive speakers significantly change attitudes to HIV and can be powerful community educators, helping to reduce fear and break down stigma.**<sup>59</sup> NGOs, particularly networks of people living with HIV, can help young men and women living with HIV to openly disclose their status and work within HIV education programmes in schools. Both public and private sector organisations can also lead HIV education sessions for in- and out-of-school youth as well as in the workplace.<sup>60</sup>

## Gender inequality and violence

In most of the world, it is adult men who hold social, political, and economic power. The lower status of women and young people relative to adult men affects every aspect of their lives, including sexual and reproductive health. Unequal power within relationships is a specific and significant barrier to improving sexual and reproductive health, and gender inequality in itself is a violation of human rights. Societal inequalities also put women and young people at increased risk of HIV infection and make it more difficult for them to obtain testing and counselling, prevention, treatment, care, and support.

Women who need their husbands' permission to go to a health clinic or to use birth control, for example, cannot exercise their rights to make free decisions about contraception and pregnancy. Women living with HIV whose husbands die may become further marginalised, as they often lose their rights to family property and resources. Girls in particular are often expected to abstain from sex, which makes them reluctant to seek information and services related to sexual and reproductive health.

Violence also increases women's vulnerability to HIV, and many anti-violence efforts focus on reducing this risk. Violence and rape lower self-esteem, increase the risk of contracting STIs, and can lead to unintended pregnancy, miscarriage, and unsafe abortion. Less attention has been paid to the violence experienced by women living with HIV. Violence, or the fear of violence, can prevent HIV-positive women from obtaining health care.<sup>61</sup> Young people living with HIV may face violence from their partners, families, and communities, especially when they disclose their status. **Advocates should press for the recognition of marital rape as a crime. They should also work to involve men and boys in programmes to stop gender-based violence.** Men need support in recognising and overcoming the ways that traditional norms of masculinity place themselves and their partners at risk.





In these circumstances, women and young people may be reluctant to talk about sex and inhibited from speaking out about their needs. Young people are rarely consulted when policies and programmes are developed, even policies and programmes aimed at them. This makes it difficult for women and young people to advocate for their sexual and reproductive rights. Even when they are willing to speak out, they may lack adequate platforms, as in many places adult men dominate non-governmental organisations and national networks of people living with HIV, and, when they are

involved in policymaking, their work often goes unrecognised.



Advocates must do more to ensure that women and young people have the information, training, and support they need to speak out on behalf of their own needs. For example, **wherever a representative position is held by a man, it is important to ensure**

**a woman is engaged as an alternative representative and is provided with skills and information so that she can take on the position of responsibility.** Women and young people living with HIV need opportunities to build self-esteem before they can begin to advocate to and negotiate with policymakers. Advocates can also work within communities to overcome societal barriers to more equitable political participation.

### **Marginalisation**

Around the world, marginalisation increases vulnerability to HIV infection. Marginalised groups often face barriers to accessing health and other services, economic inequalities, abuse and exploitation. These problems are exacerbated with a HIV diagnosis, which leaves the individual facing dual discrimination and unmet prevention, treatment, care and support needs.

It is important for advocacy organisations to realise that members of vulnerable populations have particular concerns that need to be addressed. Women and men from ethnic minorities or those who have emigrated from other countries, for example, may not sufficiently understand

the language in which health services, including informed consent information and counselling, are provided. They may also need health workers who are trained to be sensitive to different cultural practices and preferences.

Many men who have sex with men also have sexual relationships with women. They may miss out on important information directed at men who are openly gay, which can exacerbate risk for themselves, their partners, and their children. Health workers may assume that lesbians do not need sexual and reproductive health information and services. Transgender people are even less likely to be offered reproductive health information, as their very existence is not legally or socially recognised in many countries.

People in prison are on the margins of society, rarely have access to quality health care (even condom supplies), and are generally unable to exercise their political rights. Sex workers, too, may have difficulty obtaining health care and may also need help building their self-esteem so they can better negotiate safer sex. By working with law enforcement agencies to create safer environments for sex workers, advocates can directly improve access to health services and also make it easier for sex workers living with HIV to speak out on behalf of their own needs. HIV services aimed at injecting drug users generally focus on preventing transmission directly related to drug use (such as needle exchange programmes). Because drug users are likely to take sexual risks as well, they also need sexual and reproductive health care – but fear of stigma and disapproval may keep them away from health services. Advocates could push for integrating sexual and reproductive health care into drug-related harm reduction programmes to better serve this group.

Persons with disabilities have generally been left out of HIV and related sexual and reproductive health services. Service providers are not always knowledgeable about disability issues, or they may have misinformed or stigmatizing attitudes towards persons with disabilities, including beliefs that persons with disabilities are not sexually active or do not engage in risk behaviours. Services may be physically inaccessible, or fail to provide information in alternative formats (e.g., Braille, audio, and plain language). There is also the discrimination faced by persons with disabilities: In some places, where treatment demand exceeds supply, persons with disabilities may be considered a low priority for HIV treatment. **Networks of people living with HIV should form**



alliances with groups of persons with disabilities to carry out joint advocacy campaigns for programmes and services to address sexual and reproductive health, including HIV prevention, treatment, care and support.<sup>62</sup>

Members of marginalised groups may be reluctant or unable to become involved in advocacy even though they have specific, unmet needs, and, when they do become involved, their voices are not necessarily heard even within national networks of people living with HIV. It can be constructive to organise peer support groups specifically focused on the needs of marginalised groups. Peer support groups are hubs of HIV activism, important arenas for exchanging information and experiences, and invaluable sources of emotional support.

In general, advocates must be aware of the range of experiences and needs of people living with HIV, and work to diversify their networks. In partnership with groups focused on, for example, sex workers' rights, advocates can also help build knowledge and skills needed for HIV- and sexual and reproductive health-related advocacy, enabling members of marginalised groups to speak up on behalf of their own rights.

### Poverty

Persistent poverty erodes people's health and their ability to advocate for their rights. Conversely, ill health itself can lead to or exacerbate poverty. People with inadequate incomes may not be able to afford or to reach appropriate health care, especially if they live far from a health clinic. Looking after one's own health may take low priority if one is struggling to feed one's children. Juggling these concerns, an HIV-positive person living in poverty is hard-pressed to find time and energy to engage in advocacy activities.

HIV-positive women, particularly widows, are more likely to be impoverished than their male peers. Discriminatory property and inheritance laws force some widowed women and their children to leave their homes and communities, and other women are driven from their families and jobs following an HIV diagnosis. Some poor women resort to selling sex, dramatically increasing their vulnerability to STIs, unintended pregnancies, and other reproductive health problems. Poor women living with HIV are often malnourished, which increases their vulnerability to opportunistic infections. In addition, some women living with HIV sell their antiretroviral medications in order to

get money to feed themselves and their children. Advocates for treatment access must keep in mind the importance of nutrition in ensuring that treatment is adhered to and effective.<sup>63</sup>

For these reasons, **income-generating opportunities must be considered more seriously as part of the overall health of people living with HIV.** Micro-credit programmes should be supported, particularly for widows with children, older relatives looking after orphans, and child-headed household. People living with HIV need equal access to land, financial resources, and employment opportunities—and such opportunities need to be expanded for everyone. By **training, mentoring, and directly employing more people living with HIV,** governments and NGOs will help fight poverty and directly improve the health of those involved. They will also improve the overall quality of policies and programmes by incorporating the experiences of those directly affected.

### Lack of collaboration

At the national and international levels, new structures have been developed to deal with HIV and AIDS, separate from and parallel to the sexual and reproductive health care system. This parallel structure is mirrored to some extent within the advocacy community, which is fragmented in other ways as well. Women's reproductive health discussions have largely happened without men, while sexual health issues relating to men who have sex with men, sex workers, or drug users have been addressed in isolation.

Women and men need to collaborate to realise the vision of sexual and reproductive rights for all. **Groups of people living with HIV should develop common policy platforms with groups of drug users, men who have sex with men, transgender people, sex workers, migrants, ethnic minorities, refugees, and prisoners.** Young HIV-positive women and men must be provided with opportunities for genuine input into broad advocacy planning, not simply youth group activities.

Even within groups of people living with HIV, it is sometimes difficult to recognise a common agenda. For example, widows may find it challenging to work alongside sex workers. It is important to share experiences, overcome prejudice, and realise common ground. At times, real differences need to be recognised and nurtured. Sex workers, men who have sex with men, and women, for example, may need their own forums

to ensure that specific needs are discussed without prejudice from others. The important thing is to ensure that these needs are incorporated into the advocacy agenda.

## II. Improving Advocacy

Overcoming the barriers discussed above will require a concerted advocacy effort on the part of people living with HIV and their allies and champions. To make this possible, organisations and networks will need to be strengthened with new skills and alliances. Each group will have to set priorities based on the needs of the people represented, and develop partnerships with organisations who have overlapping constituencies and concerns to ensure, collectively, that the full range of sexual and reproductive health issues is addressed.

### Rely on the unique expertise of people living with HIV

As articulated in the GIPA Principle, people living with HIV have an essential role to play in the design and implementation of HIV and AIDS policies and programmes.<sup>64</sup> Women and men living with HIV – including young people and people from marginalised groups – are also critical to the success of positive prevention and can educate their peers and the public about the benefits of antiretroviral therapy, thus encouraging more people to come forward for HIV testing.

Involving people living with HIV in outreach and advocacy work also has a significant impact on changing attitudes to HIV and reducing HIV-related stigma.<sup>65</sup>

The Global Fund now requires that people living with HIV be represented in Country Coordinating Mechanisms (CCMs), providing a valuable opening for inclusion. In some countries, however, it

has been difficult for HIV-positive representatives to get their voices heard and their concerns addressed on CCMs. GNP+ has developed a tool to guide people living with HIV in their involvement in CCMs, which advocates can use to strengthen their work.

Governments and NGOs can make some simple changes to make it easier for people living with HIV to have constructive input. For example, people living with HIV need adequate notice before meetings are held to find time to participate – especially since many advocates living with HIV serve as volunteers – and to consult with their peers about the issues to be decided. The fact that people living with HIV who attend decision-making meetings are often volunteers serving among paid workers also needs to be taken into account when requesting follow-up work.

Rather than constantly calling upon a few high profile, highly educated HIV-positive people, the overall capacity of networks of people living with HIV should be strengthened. Advocacy groups should expand the opportunities for people living with HIV to be compensated for their work. **It is important to encourage, train, and pay HIV-positive people as educators, counsellors, researchers, programme designers, and policy-makers.** Employing people living with HIV in these roles helps to provide sustainable livelihoods and at the same contributes to a more successful HIV response.

Advocates working on HIV programmes can consult the NGO Code of Good Practice<sup>66</sup>, which outlines principles of good practice, including the meaningful involvement of people living with HIV. The Code includes self-assessment tools, including one for advocacy, to help organisations assess to what extent they are implementing the Code's principles. Networks and organisations of people living with HIV have helped to create and refine the code and the self-assessment tools.

### Provide education and training

Policies that bolster participation of HIV-positive people must also ensure that the people who are representing the community have the skills to do so. First and foremost, people diagnosed with HIV need education about their human rights, including those related to their sexual and reproductive health. Most people diagnosed as HIV-positive voluntarily and willingly take on the responsibility not to infect others, yet many are not aware that they have any right to be treated with dignity and respect in return.

Women and men living with HIV need training so that they can have meaningful involvement and participation on all decision-making bodies relevant to their lives, such as United Nations bodies, Global Fund committees, national



AIDS commissions, NGOs, health departments, or education curriculum development units. They need time and resources to be able to share experiences within and beyond their networks and to feed material into key decision-making at local, national, regional, and international levels. They may need mentoring by local and international NGOs on what to expect and how best to respond.

Sympathetic local and international NGOs can provide opportunities for capacity building, particularly in self-esteem, assertiveness, negotiation, and human rights, as well as basic health information. Networks of people living with HIV and international donors can also work together to enhance the advocacy skills of people living with HIV. Women living with HIV in particular are under-represented, and often lack confidence and experience within the HIV sector. Young women living with HIV who are interested and motivated to be involved in advocacy should be nurtured and mentored. Because existing training modules tend to focus on women and girls, additional modules for men living with HIV and other vulnerable populations should be developed. International NGO support for intensive training workshops on sexual and reproductive health and rights for all HIV-positive people's groups is a sound investment.

ICW has led sexual and reproductive health workshops with positive women in many parts of the world. For example, ICW and the Burkina Faso-based Responsibility, Hope, Life Association organised a 'Voices and Choices' workshop in 2003 for HIV-positive women from Francophone Africa, focused on the sexual and reproductive rights and experiences of women living with HIV. ICW has also paid particular attention to young women's needs through 'Young Women's Dialogues' where women from Namibia, South Africa, and Swaziland have come together to develop advocacy agendas related to their sexual and reproductive health, access to care, treatment, and support, and the meaningful involvement of young HIV-positive women in decisions that affect their lives.

### **Collect policy-relevant evidence**

Advocacy's greatest ally is evidence. People living with HIV need to develop more efficient ways to share, analyse, and use information. A respected body of evidence can back up advocacy arguments and enable groups of people living with HIV to counter arguments from decision-makers who attempt to justify poor policies, such as aggressive 'opt-out' HIV testing

protocols or routine male circumcision. More effective and accountable mechanisms are needed to bring the diverse voices of people living with HIV from the community level to national, regional, and international levels without creating an additional burden of reporting. This can be achieved by **linking with established research institutions to get issues important to people living with HIV onto the agenda of these institutions, and by strengthening networks of people living with HIV at the local level so they are capable of systematically collecting data.**

There are already good examples of research being used effectively in advocacy and in improving sexual and reproductive health among people living with HIV. For example, in 2001 ICW initiated a participatory research programme focusing on women's experience of living with HIV in Thailand and Zimbabwe. More recently, EngenderHealth, UNFPA, and ICW used qualitative research conducted among women living with HIV in Brazil, Ethiopia, and Ukraine to develop a training manual on sexual and reproductive health for women and girls.<sup>67</sup>

GNP+, ICW, IPPF, and UNAIDS have developed the People Living with HIV Stigma Index to measure levels of AIDS-related stigma and discrimination experienced by people living with HIV.<sup>68</sup> The tool can be used in a variety of settings to better document the experiences of people living with HIV, and with that information, develop focused advocacy for programmes and actions to help reduce HIV-related stigma in communities and specific sectors. Many of the survey questions are broadly relevant to sexual and reproductive health, and a number of them seek to identify what percentage of people living with HIV have been affected by human rights violations in healthcare settings (e.g., HIV testing without consent; breach of confidentiality; coerced sterilisation; advised not to have children due to HIV status).

In the first project to document the nature and extent of AIDS-related discrimination, the Asia Pacific Network of People living with HIV collected data from more than 760 people living with HIV in India, Indonesia, the Philippines, and Thailand.<sup>69</sup> They found that most people diagnosed with HIV face discrimination, particularly within the health sector. Discrimination from the community was aimed mostly at women living with HIV. In addition, the study showed that people who are coerced into testing face significantly more discrimination than people who choose voluntarily to test.

GNP+ is currently developing the programme *Human Rights Count!*, which will document human rights violations experienced by people living with HIV and their advocates. Violations reported by people living with HIV will be compiled into an online database and analysed by human rights experts for validation and follow-up.

Findings from research programmes are being used in advocacy efforts internationally to raise awareness of human rights violations of people living with HIV. More needs to be done, however, to use such findings to advocate for specific programmes at national and community levels to prevent such violations, and provide redress where they occur. In addition, the process of training positive people to collect data should be expanded as part of efforts to increase ‘human rights literacy’ and support people to realise their rights. To date, many people living with HIV who have started in community-based research have gone on to become actively involved in national advocacy efforts. Future research efforts should continue to include people living with HIV as active participants.<sup>70</sup>

### **Monitor and evaluate**

Advocates can also do more to ensure that policies and programmes, once in place, are actually implemented and that they work the way they are intended to. Many groups have developed useful tools and frameworks for monitoring and evaluation.

For example, HIV-positive women in Lesotho and Swaziland devised a tool to monitor access to care, treatment and support, sexual and reproductive health and rights, and violence against women. The tool provides a useful framework for bringing diverse groups together, helping health providers and government officials to think critically about the impact of their actions on HIV-positive women, and reducing the isolation faced by women living with HIV. In another project, Ipas and ICW helped develop a monitoring tool to examine benchmarks related to three of the MDGs relevant to women’s reproductive health. The tool has been tested and refined in Argentina, Botswana, Kenya, Lesotho, Mexico, Namibia, Nigeria, Peru, Poland, South Africa, and Swaziland.<sup>71</sup>

International human rights treaties, such as the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the International Covenant on Civil and Political Rights, and the International

Covenant on Cultural, Economic and Social Rights, can also be used as advocacy tools. Governments that ratify such treaties make a commitment that the laws in their country reflect the provisions of the treaty. However, this is not always the case, and even where it is, implementation of the law is often weak. People living with HIV can work together with international and national human rights NGOs to advocate that governments acknowledge and legalise same sex relations between consenting adults, sex work, and harm reduction programmes as critical parts of their efforts to support a successful response to HIV, and to protect human rights.

**To the extent that supportive laws and policies already exist, advocates must monitor their implementation.** At the international level, civil society can submit ‘shadow reports’ on the sexual and reproductive rights of people living with HIV to the human rights treaty monitoring committees.<sup>72</sup> These committees review periodic reports from governments on how they are complying with their human rights commitments and issue public recommendations to governments on the basis of their review, which are often reported in the national media. The system of shadow reports enables advocates and citizens to provide supplementary information that the committees can use when developing their recommendations. The recommendations of the committees can also be used in advocacy efforts, demanding that governments take steps towards their implementation.<sup>73</sup>

In some cases, countries have not yet ratified treaties that have important implications for the sexual and reproductive health of people living with HIV. For example, relatively few countries have ratified the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families. By participating in campaigns for treaty ratification, people living with HIV can call upon their governments to accept the standards found in the treaty and change laws, policies and programmes to be in conformity. Among other things, the Committee responsible for monitoring implementation of the treaty has called upon countries to remove mandatory HIV testing of migrant workers, and stop entry restrictions to countries based on HIV status.

Annual reviews of progress toward the Declaration of Commitment on HIV/AIDS (‘UNGASS Declaration’) offer an opportunity to monitor HIV responses and engage in advocacy. Civil society can participate in efforts to develop

the official national report that is submitted to the United Nations, or they can develop an independent shadow report that raises priority issues that may not have been addressed in detail in the main report.

### **Strengthen networks and alliances**

International NGOs have the institutional resources and skills to help ensure the continued development of networks and self-help groups of people living with HIV. Advocates and allies can provide guidance to organisations of people living with HIV on how to undertake strong organisational development and ensure good governance. They can help to train representatives who can liaise well with government officials, and mentor HIV-positive individuals for roles in the health and community sectors, among others.

Existing strong networks of people living with HIV can also play this role for groups in other areas. For example, when Igat Hope, Papua New Guinea's national organisation for people living with HIV, first formed, members had no experience in how to run a network and were not represented on any national committees. The Australian National Association of People living with HIV (NAPWA) recognised the need to enhance the skills of their neighbouring peers. NAPWA obtained funds for two representatives to visit Igat Hope and provide organisational development training several times over a two-year period. Igat Hope now has a fully functioning Board of Directors, a strong governance structure, a paid full-time coordinator, and is increasingly asked to be involved in HIV-related policy decisions. More relationships like this must be developed and nurtured.

Stronger links are also needed between the local, national, regional, and international responses to HIV, and among organisations of people living with HIV, health professionals, governments, and the media. In addition, HIV-focused activists can make important contributions to the broader sexual and reproductive health advocacy agenda through partnership with other groups. These include harm reduction networks, women's rights organisations, youth groups, human rights bodies, and organisations representing sex workers, men who have sex with men, transgender people, migrants, prisoners, refugees, and ethnic minorities. Advocates can also become more proactive in getting involved in local health and education departments, migrant organisations, and labour unions. Strategic partnerships can help to strengthen the

advocacy efforts of networks of people living with HIV. People living with HIV need to be clear on their own agenda so that they are not subsumed into the agenda of other organisations. However, they should also be willing to address issues of concern to their coalition partners' work.

## **III. Empowerment and Health Through More Effective Advocacy**

Networks of people living with HIV along with their partners and allies will be the ones to take the lead in pressing for policies and programmes that take account of the fact that most HIV-positive people are sexually active and require sexual and reproductive health care. An HIV diagnosis does not take away a person's right to have sex or bear children. It does mean that people may need additional or different information and services to protect their sexual and reproductive health, and that of their sexual partners.

People living with HIV must overcome a range of economic, social, cultural, and political barriers to effectively advocate for their needs and rights. Advocacy organisations must work to minimise these barriers. It is important to continue to strengthen the capacity of networks of people living with HIV so that their voices can inform policies and programmes. This includes general organisational development and advocacy skills, as well as specific information and training related to sexual and reproductive health and human rights.

Advocacy efforts should focus on priority issues and call for specific policies and services, including sex education, HIV testing and counselling, contraception, safe abortion, pregnancy and childbirth services, counselling on breastfeeding and alternative feeding options, as well as programmes to address poverty and violence. At all times, advocates must stress the meaningful involvement of people living with HIV – especially women and members of marginalised groups – in the development, implementation, and monitoring of laws and programmes. Ultimately, following the lead of those who are most affected will enable decision-makers to respond with effective sexual and reproductive health services. And taking the lead in defining and evaluating policies and practice will ensure that people living with HIV are aware of their rights and empowered to act when these rights are violated or left unrealised.



## PUTTING THE PIECES TOGETHER: PARLIAMENTARIANS FOR WOMEN'S HEALTH

The Parliamentarians for Women's Health project is designed to help policymakers in Botswana, Namibia, Kenya, and Tanzania better understand the health challenges that women, especially HIV-positive women, face.<sup>74</sup> It is a partnership between ICW, Centre for the Study of AIDS (University of Pretoria), the International Center for Research on Women, and Realizing Rights: the Ethical Globalisation Initiative. This project, particularly as it has unfolded in Namibia, serves as a model for how effective advocacy work can advance the sexual and reproductive health and rights of people living with HIV.

In Namibia, the project began with evidence gathering. Women living with HIV conducted the research themselves in two stages. First, HIV-positive women's groups in four locations worked to map their experiences with obtaining health care. They identified the factors that make it difficult for them to maintain good health, including poverty, hunger, HIV-related stigma, lack of decision-making power in the household, and insufficient health commodities and equipment. Next, ICW conducted three regional community assessments, which included site visits to health care facilities and workshops with women, community leaders, and health workers. These assessments reinforced the findings from the mapping exercise and added new dimensions by exploring the attitudes and priorities of health workers and the actual health infrastructures available.

The results of this research were shared with parliamentarians and health professionals at a roundtable meeting. At the meeting, the Deputy Home Affairs Minister described more generally how gender disparities, poverty, social exclusion, unemployment, and poor housing damage women's health. Her presentation underscored the national scope of the problems identified and demonstrated that the government is serious about finding solutions. Participants at the roundtable recommended attacking the problems from several directions, including a national awareness campaign on HIV and sexual and reproductive health that includes people living with HIV, stronger dialogue on gender issues between parliamentarians and ministries focused on women's and children's welfare, and shelters, support, and legal services for abused women and children.

Following the roundtable, the project trained a small group of female parliamentarians and HIV-positive young women from the Namibia Women's Health Network (NWHN) on sexual and reproductive health and rights. These women in turn have begun to train others, eventually spreading information to women across Namibia. In addition, organisers have partnered with the Namibia Institute of Democracy and the Legal Assistance Centre to help HIV-positive women understand their legal rights and build advocacy skills. As women are educated and trained, they are also involved in monitoring service delivery and talking to community members so that they can bring important issues to policy-makers.

After participating in the research and training, one group of women directly approached the Ministry of Health to request improved access to cancer prevention services, such as Pap tests and breast examinations. As a result, the Ministry began collaborating with the private Cancer Association to expand access to cancer information and care. Participants have also worked to call attention to the forced sterilization of women living with HIV and have gathered evidence in support of efforts to legalise safe abortion.

In addition, parliamentarians and the Ministry of Health and Social Services asked NWHN to coordinate a review of the draft National AIDS Policy by civil society organisations, particularly groups of people living with HIV. The final document reflects changes made by this group, and NWHN now participates on the Global Fund committee in Namibia's Ministry of Health and Social Services.

The Parliamentarians for Women's Health project is ensuring that HIV-positive women are meaningfully involved in decision-making, including national policies that impact on their lives. It has identified and addressed some of the major challenges to effective advocacy around sexual and reproductive health, including stigma and discrimination, patriarchal attitudes, and poverty. It utilises education and training, policy-relevant research, and alliances with health providers, governments, and NGOs to build an informed and empowered advocacy movement. Efforts like these promise to improve policies, programmes, and action for the sexual and reproductive health and rights of people living with HIV.





# APPENDIXES



# APPENDIX 1

## MORE INFORMATION AND USEFUL TOOLS

### General information on Sexual and Reproductive Health and Rights of People Living with HIV

This Guidance Package is based upon a set of more extensive background papers developed by the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV/AIDS (ICW), Young Positives, EngenderHealth, International Planned Parenthood Federation (IPPF), the Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Population Fund (UNFPA), and the World Health Organization (WHO):

Hawkins, K. (2007). *Creating a supportive health system to ensure the sexual and reproductive health of people living with HIV: A guide.* (unpublished).

Doupe, A. (2007). *Creating a supportive and enabling environment for the sexual and reproductive health of people living with HIV: Legal and policy considerations with recommendations.* (unpublished).

Paxton, S. (2007). *Advocacy relating to the sexual and reproductive health and rights of people living with HIV.* (unpublished).

*Global consultation on the sexual and reproductive health and rights of people living with HIV: Consultation report.* (2007). Amsterdam, Global Network of People Living with HIV, International Community of Women Living with HIV/AIDS, and Young Positives. [www.gnpplus.net/component/option,com\\_docman/task,doc\\_download/gid,268/Itemid,53](http://www.gnpplus.net/component/option,com_docman/task,doc_download/gid,268/Itemid,53)

*Reproductive Health Matters.* (2007). 15(29, Suppl.). [www.who.int/reproductive-health/hiv/docs.html](http://www.who.int/reproductive-health/hiv/docs.html)

- Six of the background papers prepared for the Addis Ababa consultation on the rights of people living with HIV to sexual and reproductive health were published in this supplement.

*Global consultation on the rights of people living with HIV to sexual and reproductive health: Meeting report.* (2006). Addis Ababa, UNFPA, WHO, and EngenderHealth. [www.who.int/reproductive-health/hiv/final\\_global\\_consultation.pdf](http://www.who.int/reproductive-health/hiv/final_global_consultation.pdf)

*Fact sheet: Sexual and reproductive health and rights.* (2006). London, International Community of Women Living with HIV/AIDS and the Global Coalition on Women and AIDS. [www.icw.org/files/SRHR-ICW%20fact%20sheet-06.doc](http://www.icw.org/files/SRHR-ICW%20fact%20sheet-06.doc)

*Meeting the sexual and reproductive health needs of people living with HIV.* (2006). New York and Geneva, Guttmacher Institute and UNAIDS. [www.guttmacher.org/pubs/IB\\_HIV.html](http://www.guttmacher.org/pubs/IB_HIV.html)

- This policy brief discusses some of the specific sexual and reproductive health needs of people living with HIV and outlines the challenges and benefits to meeting these needs.

*Sexual and reproductive health and HIV/AIDS – A framework for priority linkages.* (2005). London, New York, and Geneva, IPPF, UNFPA, UNAIDS, and WHO. [www.who.int/reproductive-health/stis/docs/framework\\_priority\\_linkages.pdf](http://www.who.int/reproductive-health/stis/docs/framework_priority_linkages.pdf)

- A short document proposing policy and programme actions to strengthen linkages between sexual and reproductive health and HIV/AIDS programmes. Also available in French and Spanish.

### Specific issues and groups of people living with HIV

*Women and girls living with HIV/AIDS: Overview and annotated Bibliography.* (2007). Brighton, BRIDGE and the International Community of Women Living with HIV/AIDS. [www.siyanda.org/Static/esplen\\_women\\_hiv.htm](http://www.siyanda.org/Static/esplen_women_hiv.htm)

*Essential Medicines for Reproductive Health: Guiding Principles for Their Inclusion on National Medicines Lists.* (2006). Seattle, PATH, WHO and the UNFPA. [www.who.int/reproductive-health/publications/essential\\_medicines/emls\\_guidingprinciples.pdf](http://www.who.int/reproductive-health/publications/essential_medicines/emls_guidingprinciples.pdf)

- Reproductive health programme managers, national-level essential medicines committees, and those responsible for selecting, procuring, and ensuring the quality of reproductive health medicines can use this guide to better understand the process for developing essential medicines lists and how to incorporate key reproductive health medicines.

*HIV/AIDS prevention, care, treatment and support in prison settings: A framework for an effective national response.* (2006). New York, United Nations, WHO and Joint United Nations Programme on HIV/AIDS. [data.unaids.org/pub/Report/2006/20060701\\_HIV-AIDS\\_prisons\\_en.pdf](http://data.unaids.org/pub/Report/2006/20060701_HIV-AIDS_prisons_en.pdf)

*HIV/AIDS prevention, care, treatment and support in prison settings: A framework for an effective national response.* (2006). New York, United Nations, WHO and Joint United Nations Programme on HIV/AIDS. [data.unaids.org/pub/Report/2006/20060701\\_HIV-AIDS\\_prisons\\_en.pdf](http://data.unaids.org/pub/Report/2006/20060701_HIV-AIDS_prisons_en.pdf)

- Sets out a series of principles and concrete actions to ensure that prisoners have access to the same prevention, care, treatment, and support for HIV/AIDS that is available to people outside of prison; prevent the spread of HIV and other infections; and promote an integrated approach to health care within prisons to tackle wider public health issues.

*Sexual and reproductive health of women living with HIV/AIDS – Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings.* (2006). Geneva, WHO and UNFPA. [www.who.int/reproductive-health/docs/srhwomen\\_hivaids/text.pdf](http://www.who.int/reproductive-health/docs/srhwomen_hivaids/text.pdf)

- Addresses the specific sexual and reproductive health needs of women living with HIV/AIDS. Includes recommendations for counselling, antiretroviral therapy, care, and other interventions.

*The Yogyakarta Principles: Principles on the application of international human rights law in relation to sexual orientation and gender identity.* (2006). Yogyakarta, International Commission of Jurists and the International Service for Human Rights. [www.yogyakartaprinciples.org/docs/File/Yogyakarta\\_Principles\\_EN.pdf](http://www.yogyakartaprinciples.org/docs/File/Yogyakarta_Principles_EN.pdf)

- Based on international human rights agreements, these Principles apply existing human rights standards to issues of sexual orientation and gender identity, including extrajudicial executions, violence and torture, access to justice, privacy, non-discrimination, rights to freedom of expression and assembly, employment, health, education, immigration and refugee issues, and public participation.

*Challenging, changing and mobilizing: A guide to people living with HIV involvement in Country Coordinating Mechanisms.* (2005). Amsterdam, Global Network of People Living with HIV. [www.gnpplus.net/cms-downloads/files/handbook-EN.pdf](http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf)

- A practical guide for people living with HIV who wish to become more involved in their country's work with the Global Fund.

*How to develop and implement a national drug policy – 2nd edition.* (2001). Geneva, WHO. [www.who.int/medicines/areas/policy/en](http://www.who.int/medicines/areas/policy/en)

- These updated guidelines focus on current problems and new challenges in the national drug policy process. Each chapter presents strategies and practical approaches that can be used to improve the situation.

### Training manuals and tools

*Sexual and reproductive health for HIV-Positive women and adolescent girls: A manual for trainers and programme managers.* (2006). New York, EngenderHealth and the International Community of Women Living with HIV/AIDS. [www.engenderhealth.org/files/pubs/hiv-aids-stis/SRH\\_for\\_HIV\\_Positive\\_Women\\_English.pdf](http://www.engenderhealth.org/files/pubs/hiv-aids-stis/SRH_for_HIV_Positive_Women_English.pdf)

- Provides information and a structure for a four-day training and a two-day planning workshop. Also available in French, Portuguese, Russian, and Spanish.

*Reproductive choices and family planning for people living with HIV.* (2006). Geneva, WHO. [www.who.int/reproductive-health/publications/fphiv\\_flipchart/index.htm](http://www.who.int/reproductive-health/publications/fphiv_flipchart/index.htm)

- This tool is designed to help health workers counsel people living with HIV on sexual and reproductive choices and family planning. It can also help people living with HIV make and carry out informed, healthy, and appropriate decisions about their sexual and reproductive lives.

*Reducing stigma and discrimination related to HIV and AIDS: Training for health care workers.* (2004). New York, EngenderHealth. [www.engenderhealth.org/res/offc/hiv/stigma/index.html#stigma](http://www.engenderhealth.org/res/offc/hiv/stigma/index.html#stigma)

- Addresses the root causes of stigma and discrimination, health care providers' attitudes about HIV and AIDS, clients' rights in receiving health care services, and proper infection prevention techniques to help minimize the risk of occupational exposure to HIV. Trainer's manual and participants' handbook available in English and French.

### Monitoring and advocacy tools

*Positive women monitoring change: A monitoring tool on access to care, treatment and support sexual and reproductive health and rights and violence against women created by and for HIV positive women.* (2006, updated). London, International Community of Women Living with HIV/AIDS. [www.icw.org/files/monitoringchangetool-designed.doc](http://www.icw.org/files/monitoringchangetool-designed.doc)

- A tool positive women can use to monitor government commitments to HIV-positive women's rights. The package also includes supporting resources on sexual and reproductive health; access to treatment, care, and support, and violence against women.

*Fulfilling reproductive rights for women affected by HIV/AIDS. A tool for monitoring progress toward three Millennium Development Goals.* (2006). Chapel Hill, NC, Ipas. [www.ipas.org/Publications/asset\\_upload\\_file245\\_2897.pdf](http://www.ipas.org/Publications/asset_upload_file245_2897.pdf)

- Supplies questions that organizations serving women living with HIV can use to assess essential areas of care and advocacy, including provision of antiretroviral medications, information about international agreements about the rights of people living

with HIV, and the broader inclusion of people living with HIV into program development and evaluation.

*Code of good practice for NGOs responding to HIV/AIDS.*  
[www.hivcode.org](http://www.hivcode.org)

- This website includes self-assessment checklists that NGOs can use to measure their progress in mainstreaming HIV, ensuring the meaningful involvement of people living with HIV, countering stigma and discrimination and supporting voluntary counselling and testing.

### **International declarations and human rights treaties**

*Universal Declaration of Human Rights.* (1948). Paris, United Nations General Assembly. [www.unhchr.ch/udhr/lang/eng.htm](http://www.unhchr.ch/udhr/lang/eng.htm)

*International Convention of the Elimination of All Forms of Racial Discrimination.* (1965). New York, United Nations General Assembly. Entry into force: 1969. [www2.ohchr.org/english/law/cerd.htm](http://www2.ohchr.org/english/law/cerd.htm)

*Convention on the Elimination of All Forms of Discrimination Against Women.* (1979). New York, United Nations General Assembly. Entry into force: 1979. [www2.ohchr.org/english/law/cedaw.htm](http://www2.ohchr.org/english/law/cedaw.htm)

*Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.* (1984). New York., United Nations General Assembly. Entry into force: 1987. [www2.ohchr.org/english/law/cat.htm](http://www2.ohchr.org/english/law/cat.htm)

*Convention on the Rights of the Child.* (1989). New York, United Nations General Assembly. Entry into force: 1990. [www2.ohchr.org/english/law/crc.htm](http://www2.ohchr.org/english/law/crc.htm)

*International Covenant on Civil and Political Rights.* (1966). New York, United Nations General Assembly. Entry into force: 1976. [www.unhchr.ch/html/menu3/b/a\\_ccpr.htm](http://www.unhchr.ch/html/menu3/b/a_ccpr.htm)

*International Covenant on Economic, Social and Cultural Rights.* (1966). New York, United Nations General Assembly. Entry into force: 1976. [www.unhchr.ch/html/menu3/b/a\\_cescr.htm](http://www.unhchr.ch/html/menu3/b/a_cescr.htm)

*International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.* (1990). New

York, United Nations General Assembly. Entry into force: 2003. [www.unhchr.ch/html/menu3/b/m\\_mwctoc.htm](http://www.unhchr.ch/html/menu3/b/m_mwctoc.htm)

*Convention on the Rights of Persons with Disabilities.* (2006). New York, United Nations General Assembly. Entry into force: 2008. [www2.ohchr.org/english/law/disabilities-convention.htm](http://www2.ohchr.org/english/law/disabilities-convention.htm)

*Declaration of Commitment on HIV/AIDS.* (2001). New York, United Nations General Assembly. [www2.ohchr.org/english/law/hiv.htm](http://www2.ohchr.org/english/law/hiv.htm)

*Political Declaration on HIV/AIDS.* (2006). New York, United Nations General Assembly. [data.unaids.org/pub/Report/2006/20060615\\_HLM\\_PoliticalDeclaration\\_ARES60262\\_en.pdf](http://data.unaids.org/pub/Report/2006/20060615_HLM_PoliticalDeclaration_ARES60262_en.pdf)



## APPENDIX 2

# LIST OF RECOMMENDATIONS

### GLOBAL CONSULTATION ON THE SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS (SRHR) OF PEOPLE LIVING WITH HIV (PLHIV), DECEMBER 2007

#### Preamble

Recognising the need for Health Systems (HS) to be holistic, flexible, creative and comprehensive to be able to include, reach and respond to the different sexual and reproductive health needs and rights of people living with HIV, attention needs to be focused on:

- Providing a comprehensive continuum of sexual and reproductive health (SRH) services for people living with HIV from birth (particularly for people born with HIV) from birth through childhood, adolescence, adulthood, and old age.
- Providing comprehensive care services and commodities for HIV-positive young and old, transgender people, men and women (e.g., cancer care, sexually transmitted infections (STIs) services, prevention of parent-to-child transmission (PPTCT), contraception and psychosocial support).
- Providing comprehensive services for women living with HIV, beyond the prevention of vertical HIV transmission, including treatment and support programmes, focusing on women's health.
- Providing access to comprehensive post-sexual assault services, including STI management, emergency contraception, and psychological support.
- Providing access to SRH commodities, including lubricants, female and male condoms, and rectal and vaginal microbicides – when and if these become available.
- Developing guidelines for health care workers to involve men in conception, PPTCT, and family planning services.

- Providing services for young prisoners, particularly those in juvenile detention, and female, male and transgender (in particular indigenous) adult prisoners.
- Providing harm reduction services that include the specific needs of HIV-positive transgender people (e.g., hormone injections, sexual reassignment surgery, and castration).
- Providing harm reduction services that include the specific needs of HIV-positive female injecting drug users including ensuring that HIV-positive pregnant opioid injecting drug users should continue to receive pre-, during- and post-natal substitution therapy.
- Involving people living with HIV in the education of health care providers.
- Involving people living with HIV, particularly HIV-positive women, in decision-making processes on SRH at all levels.
- Ensuring that people living with HIV are involved in the formulation of policy (especially where policies do not exist) and their implementation, monitoring and evaluation. This includes key populations, i.e., men who have sex with men, injecting drug users, sex workers, transgender people, indigenous people, people in detention settings, people with disabilities, and young people.

#### Involvement and Inclusion

1. In accordance with the Greater Involvement of People Living with HIV (GIPA) Principle,
  - Involve HIV-positive people, including key populations in the choice, design, implementation, monitoring and evaluation of SRH-related policy, programmes and resource allocation.
  - Provide funds for SRHR services for people living with HIV only to those organisations that demonstrate that their decision-making bodies are composed of 25% trained and capable people living with HIV (these funding criteria are for bilateral, multilateral, private, public, foundation, etc)
2. Transgender people need to be recognised in their own right and not subsumed under men who have sex with men (MSM), lesbian, gay, bisexual and transgender (LGBT) etc.
3. Global people living with HIV networks need to meaningfully include transgender people in consultation processes.
4. Men need to be more involved in reducing and eliminating gender-based violence (GBV) against women, transgender people and men through community-driven campaigns on the reduction of GBV.

## Implementation

5. SRH organisations to ensure the involvement of people living with HIV in policy and programming as well as ensuring appropriate funding support for their involvement.
6. Transgender people to be involved in the choice, design, implementation, monitoring and evaluation of SRH policy and programmes.
7. Men to be more involved in programmes and campaigns at all levels to reduce and eliminate gender-based violence (GBV) against women, transgender people and other men.

## Access

8. A comprehensive continuum of care from birth through childhood, adolescence, adulthood, and old age (particularly for people born with HIV).
9. Guidelines for health care workers to involve men in conception services, PPTCT, and family planning.
10. SRH services and commodities, including lubricants, and male and female condoms.
11. Comprehensive care services and commodities for HIV-positive transgender people (e.g., cancer care, STI services, PPTCT, contraception, psychosocial support).
12. Comprehensive services beyond prevention of vertical transmission for women living with HIV, including treatment, care and support programmes which focus on women's health.
13. Comprehensive, accessible women-friendly services. HIV-positive pregnant opioid injecting drug users should continue to receive pre-, during and post-natal substitution therapy.
14. Comprehensive post-sexual assault services, including STI management, emergency contraception and psychological care.
15. Services for young prisoners, particularly those in juvenile detention.
16. Harm reduction services to include the specific needs of HIV-positive transgender people (e.g., hormone injections, sexual reassignment surgery and castration).

## Training

17. Curriculum for new and existing health care workers to meet the SRH needs of people living with HIV (including transgender people, young people and adults), including

sensitisation on, and support for, the SRH of people living with HIV.

18. Train HIV-positive young people on advocacy.
19. Include sexual dysfunction of people living with HIV, both those on and off treatment, in training curricula.

## Legal Issues

There is a need for strong support (such as position statements, policy briefs, technical guidance documents, funding for advocacy SRHR, and lobbying with national governments) from partners (UN, governments, and civil society) to repeal laws that criminalise HIV-positive people and prevent them from fully enjoying their SRHRs. Work in this area should include:

20. Strong support from partners (UN agencies, governments and civil society) to oppose and pressure for repeal of laws criminalising HIV-positive people's rights to fully enjoy their SRH.
21. Equity in adoption laws and custody of children for HIV-positive parents.
22. Removal of laws contravening the right to marry and barriers to founding a family.

## Monitoring and Evaluation

23. Monitoring and evaluation need to be supported whereby people living with HIV can document and report instances of stigma and discrimination and SRHR violations by health care providers, including SRH and HIV providers.

## Eliminating stigma

People living with HIV should be leading initiatives that will result in eliminating stigma. These initiatives should include:

24. Mapping and monitoring of GIPA best practices.
25. Developing a tool to monitor the situation of SRHR of people living with HIV (including health care settings, policies, and programmes) and periodically monitor the situation through the people living with HIV networks, including the Global Network of People Living with HIV, the International Community of Women, Young Positives and national people living with HIV networks.

## ENDNOTES

### Chapter 1

- 1 See, for example, Office of the United Nations High Commissioner for Human Rights, *Claiming the Millennium Development Goals: A human rights approach*. (2008). New York and Geneva, United Nations. Available on-line at [www2.ohchr.org/SPdocs/Claiming\\_MDGs\\_en.pdf](http://www2.ohchr.org/SPdocs/Claiming_MDGs_en.pdf)
- 2 2005 World Summit Outcome, UN Document A/RES/60/1 See Para.57(g) where governments commit themselves to 'Achieving universal access to reproductive health by 2015, as set out at the International Conference on Population and Development, integrating this goal in strategies to attain the internationally agreed development goals, including those contained in the Millennium Declaration, aimed at reducing maternal mortality, improving maternal health, reducing child mortality, promoting gender equality, combating HIV/AIDS and eradicating poverty...' Available on-line at [www.un.org/summit2005/documents.html](http://www.un.org/summit2005/documents.html)
- 3 In early 2008 the Swiss National AIDS Commission (EKAF) released a statement on risk of HIV transmission while on antiretroviral treatment and in the absence of other STIs. The Commission states that 'an HIV-infected person on antiretroviral therapy with completely suppressed viraemia ('effective ART') is not sexually infectious, i.e. cannot transmit HIV through sexual contact.' However, the Commission qualifies its statement, noting that it is considered valid only so long as: (a) the person adheres to antiretroviral therapy, the effects of which must be evaluated regularly by the treating physician, and (b) the viral load has been suppressed (<40 copies/ml) for at least six months, and (c) there are no other sexually transmitted infections. See Vernazza, P., et al. (2008). Les personnes séropositives ne souffrant d'aucune autre MST et

suivant un traitement antirétroviral efficace ne transmettent pas le VIH par voie sexuelle. *Bulletin des médecins suisses*, 89, 165-169. Available on-line at [www.saez.ch/pdf\\_f/2008/2008-05-089.pdf](http://www.saez.ch/pdf_f/2008/2008-05/2008-05-089.pdf). In response to the statement, UNAIDS and WHO have reiterated the importance of a comprehensive approach to HIV prevention, including correct and consistent use of condoms. The joint UNAIDS/WHO statement acknowledges that research suggests that when the viral load is undetectable in blood the risk of HIV transmission is significantly reduced, but goes on to note that it has not been proven to completely eliminate the risk of transmitting the virus. See 'Antiretroviral therapy and sexual transmission of HIV' (1 February 2008). Available on-line at [data.unaids.org/pub/PressStatement/2008/080201\\_hivtransmission\\_en.pdf](http://data.unaids.org/pub/PressStatement/2008/080201_hivtransmission_en.pdf)

- 4 *Sexual and reproductive health of women living with HIV/AIDS: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings*. (2006). UNFPA and WHO. Available on-line at [www.who.int/hiv/pub/guidelines/sexualreproductivehealth.pdf](http://www.who.int/hiv/pub/guidelines/sexualreproductivehealth.pdf)
- 5 *Global Consultation on the Rights of People Living with HIV to Sexual and Reproductive Health: Meeting Report*. (2006). Addis Ababa, Ethiopia; 27-30 March 2006. Available on-line at [www.who.int/reproductive-health/hiv/final\\_global\\_consultation.pdf](http://www.who.int/reproductive-health/hiv/final_global_consultation.pdf)
- 6 *Global Consultation on the Sexual and Reproductive Health and Rights of People Living with HIV: Consultation Report*. (2007). Global Network of People Living with HIV, International Community of Women Living with HIV/AIDS, and Young Positives. Amsterdam. [www.gnpplus.net/component/option,com\\_docman/task,doc\\_download/gid,268/Itemid,53](http://www.gnpplus.net/component/option,com_docman/task,doc_download/gid,268/Itemid,53)

- 7 'Dual protection' refers to protection from both sexually transmitted infections and unwanted pregnancy.

### Chapter 2

- 8 *Financial Resources Required to Achieve Universal Access to HIV Prevention, Treatment, Care and Support*. (2007). Geneva, UNAIDS. [data.unaids.org/pub/Report/2007/20070925\\_advocacy\\_grne2\\_en.pdf](http://data.unaids.org/pub/Report/2007/20070925_advocacy_grne2_en.pdf)
- 9 The United States President's Emergency Plan for AIDS Relief.
- 10 For a review of PEPFAR spending requirements in the area of prevention, see United States Government Accountability Office (2006), *Spending Requirement Presents Challenges for Allocating Prevention Funding under the President's Emergency Plan for AIDS Relief*. Available on-line at [www.gao.gov/new.items/do6395.pdf](http://www.gao.gov/new.items/do6395.pdf)
- 11 Dräger, S., Gedik, G. & Dal Poz, M. (2006). Health workforce issues and the Global Fund to fight AIDS, Tuberculosis and Malaria: an analytical review. *Human Resources for Health*, 4, 23. [www.human-resources-health.com/content/4/1/23/abstract](http://www.human-resources-health.com/content/4/1/23/abstract)
- 12 Background Discussion Paper No. 3 for the Interagency Consultation on the Selection and Delivery of Essential Medicines and Commodities for Reproductive Health. In *Reproductive Health Medicines in National Essential Medicines Lists: A Research Report*. (2003). Geneva, WHO; PATH, WHO and UNFPA. (2006). *Essential Medicines for Reproductive Health: Guiding Principles for Their Inclusion on National Medicines Lists*. Seattle, PATH. [www.who.int/medicines/publications/EssMeds\\_RHealth.pdf](http://www.who.int/medicines/publications/EssMeds_RHealth.pdf)
- 13 *The World Health Report 2006 – Working together for health*. (2006). Geneva, WHO. [www.who.int/entity/whr/2006/whro6\\_en.pdf](http://www.who.int/entity/whr/2006/whro6_en.pdf)

- 14 See, for example, *AIDS Discrimination in Asia*. (2004). Asia Pacific Network of People Living with HIV. Available online at [www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf](http://www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf)
- 15 For an example of a trainer's manual employing such approaches, see *Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers*. (2004). EngenderHealth. Available online at [www.engenderhealth.org/files/pubs/hiv-aids-stis/reducing\\_stigma\\_trainer\\_English.pdf](http://www.engenderhealth.org/files/pubs/hiv-aids-stis/reducing_stigma_trainer_English.pdf)
- 16 For further discussion of some of these issues, see *Treat, Train, Retain: The AIDS and Health Workforce Plan; Report on the Consultation on AIDS and Human Resources for Health*. (2006). WHO, Geneva, 11-12 May 2006. Available online at [www.who.int/hiv/pub/meetingreports/TTRmeetingreport2.pdf](http://www.who.int/hiv/pub/meetingreports/TTRmeetingreport2.pdf)
- 17 *Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa: A literature review*. (2000). Geneva, UNAIDS. [data.unaids.org/Publications/IRC-pub01/jc299-tradheal\\_en.pdf](http://data.unaids.org/Publications/IRC-pub01/jc299-tradheal_en.pdf)
- 18 Kaai, S., et al. (2004). *Experiences of postpartum women with PMTCT: the need for community-based approaches*. 11th Reproductive Health Research Priorities Conference, Sun City, South Africa, October 5-9, 2004.
- 19 *The World Health Report 2004: Changing History*. (2004). Geneva, WHO. [www.who.int/entity/whr/2004/en/report04\\_en.pdf](http://www.who.int/entity/whr/2004/en/report04_en.pdf)
- 20 An example of one such monitoring tool is the People Living with HIV Stigma Index, which includes attention to quality of HIV and sexual and reproductive health services, discrimination in healthcare settings, and other relevant issues. See [www.stigmaindex.org](http://www.stigmaindex.org) for more information and to access the user guide for the survey tool.
- 21 See also *Guidance on provider-initiated HIV testing and counselling in health facilities*. (2007). WHO and UNAIDS. Available online at [www.who.int/hiv/pub/guidelines/9789241595568\\_en.pdf](http://www.who.int/hiv/pub/guidelines/9789241595568_en.pdf)
- 22 The Committee on the Rights of the Child, the United Nations human rights treaty body responsible for monitoring the implementation of the Convention on the Rights of the Child, has stated its concern that 'health services are generally still insufficiently responsive to the needs of children under 18 years of age, in particular adolescents.' It has furthermore noted that 'children are more likely to use services that are friendly and supportive, provide a wide range of services and information, are geared to their needs, give them the opportunity to participate in decisions affecting their health, are accessible, affordable, confidential and non-judgemental, do not require parental consent and are not discriminatory.' See Committee on the Rights of the Child (2003), General Comment No. 3, 'HIV/AIDS and the Rights of the Child'. Available online at [www2.ohchr.org/english/bodies/crc/docs/GC3\\_en.doc](http://www2.ohchr.org/english/bodies/crc/docs/GC3_en.doc)
- 23 Gallant, M. & Maticka-Tyndale, E. (2004). School-based HIV prevention programmes for African youth. *Social Science and Medicine*, 58(7), 1337-1351; Magnani, R., et al. (2005). The impact of life skills education on adolescent sexual risk behaviours in KwaZulu-Natal, South Africa. *Journal of Adolescent Health*, 36(4), 289-304; Kirby, D., Laris, B.A. & Roller, L. (2005). Impact of Sex and HIV Education Programs on Sexual Behaviors of Youth in Developing and Developed Countries. *Youth Research Working Paper No. 2*. Arlington, VA, Family Health International/YouthNet.
- 24 King, R. (2005). *Collaboration With Traditional Healers in HIV/AIDS Prevention and Care in Sub-Saharan Africa: A Literature Review*. Geneva, UNAIDS. [www.hst.org.za/uploads/files/Collab\\_Lit\\_Rev.pdf#search=](http://www.hst.org.za/uploads/files/Collab_Lit_Rev.pdf#search=)
- UNAIDS%202000; Kapungwe, A.K. (2003). Traditional cultural practices of imparting sex education and the fight against HIV/AIDS: The case of initiation ceremonies for girls in Zambia. *African Sociological Review*, 7(1), 35-52. [www.codesria.org/Links/Publications/asr7\\_full/aids\\_zambia.pdf](http://www.codesria.org/Links/Publications/asr7_full/aids_zambia.pdf); Kayombo, E.J. et al. (2007). Experience of initiating collaboration with traditional healers in managing HIV and AIDS in Tanzania. *Journal of Ethnobiology and Ethnomedicine*, 3(6). [www.ethnobiomed.com/content/3/1/6](http://www.ethnobiomed.com/content/3/1/6).
- 25 *Medical Eligibility Criteria for Contraceptive Use*. (2004). Geneva, WHO. [www.who.int/reproductive-health/publications/mec/mec.pdf](http://www.who.int/reproductive-health/publications/mec/mec.pdf)
- 26 Strachan, M., et al. (2004). *An Analysis of Family Planning Content in HIV/AIDS, VCT, and PMTCT Policies in 16 Countries*. Washington, DC, Policy Project. [www.policyproject.com/pubs/workingpapers/wps-09.pdf](http://www.policyproject.com/pubs/workingpapers/wps-09.pdf).
- 27 Delvaux, T., et al. (2003). The need for family planning and safe abortion services among women sex workers seeking STI care in Cambodia. *Reproductive Health Matters*, 11(21), 88-95.
- 28 *Safe Abortion: Technical and Policy Guidance for Health Systems*. (2003). WHO, Geneva. [www.who.int/reproductive-health/publications/safe\\_abortion/safe\\_abortion.pdf](http://www.who.int/reproductive-health/publications/safe_abortion/safe_abortion.pdf).
- 29 *AIDS Discrimination in Asia*. (2004). Asia Pacific Network of People living with HIV/AIDS, Bangkok. [www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf](http://www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf); *HIV/AIDS: Reproductive Rights on the Line*. (2002). New York, Center for Reproductive Rights. [www.reproductiverights.org/pdf/bp\\_HIV\\_rroline.pdf](http://www.reproductiverights.org/pdf/bp_HIV_rroline.pdf); DeBruyn, M. (2005). *HIV/AIDS and reproductive health. Sensitive and neglected issues. A review of the literature. Recommendations for Action*. Chapel Hill, NC, Ipas.

- 30 Ross, A., et al. (2004). HIV-1 disease progression and fertility: the incidence of recognised pregnancy and pregnancy outcome in Uganda. *AIDS*, 18(5), 799-804; Lewis, J.J.C. (2004). The population impact of HIV on fertility in sub-Saharan Africa. *AIDS*, 18(Suppl. 2), S35-S43.
- 31 *Sexual and reproductive health of women living with HIV/AIDS: guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings*. (2006). Geneva, WHO and UNFPA. [www.who.int/entity/pub/guidelines/sexualreproductivehealth.pdf](http://www.who.int/entity/pub/guidelines/sexualreproductivehealth.pdf)
- 32 Coovadia, H.M., et al. (2007). Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first 6 months of life: An intervention cohort study. *The Lancet*, 369, 1107-1116. [www.thelancet.com/journals/lancet/article/PIIS0140673607602839/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140673607602839/fulltext)
- 33 Ellerbrock, T.V., et al. (2000). Incidence of cervical squamous intraepithelial lesions in HIV-infected women. *Journal of the American Medical Association*, 283(8), 1031-1037. [jama.ama-assn.org/cgi/reprint/283/8/1031.pdf](http://jama.ama-assn.org/cgi/reprint/283/8/1031.pdf); Sun, X.W., et al. (1995). Human papillomavirus infection in human immunodeficiency virus-seropositive women. *Obstetrics & Gynecology*, 85, 680-686; Östör, A.G. (1993). Natural history of cervical intraepithelial neoplasia: a critical review. *International Journal of Gynecological Pathology*, 12(2), 186-192; Lomalisa, P., Smith, T., Guidozzi, F. (2000). Human immunodeficiency virus infection and invasive cervical cancer in South Africa. *Gynecologic Oncology*, 77(3), 460-463.
- Chapter 3**
- 34 WHO Constitution. (1946). Geneva, WHO. [www.who.int/governance/eb/who\\_constitution\\_en.pdf](http://www.who.int/governance/eb/who_constitution_en.pdf); Article 25. *Universal Declaration of Human Rights*. (1948). Paris, United Nations General Assembly. [www.unhchr.ch/udhr/lang/eng.htm](http://www.unhchr.ch/udhr/lang/eng.htm); Article 5. *Convention on the Elimination of All Forms of Racial Discrimination*. (1965). New York, United Nations General Assembly. Entry into force: 1969. [www2.ohchr.org/english/law/cerdc.htm](http://www2.ohchr.org/english/law/cerdc.htm); Articles 7, 11 and 12. *International Covenant on Economic, Social and Cultural Rights*. (1966). New York, United Nations General Assembly. Entry into force: 1976. [www.unhchr.ch/html/menu3/b/a\\_ceschr.htm](http://www.unhchr.ch/html/menu3/b/a_ceschr.htm); Articles 10, 12 and 14. *Convention on the Elimination of All Forms of Discrimination Against Women*. (1979). New York, United Nations General Assembly. Entry into force: 1979. [www2.ohchr.org/english/law/cedaw.htm](http://www2.ohchr.org/english/law/cedaw.htm); Article 24. *Convention on the Rights of the Child*. (1989). New York, United Nations General Assembly. Entry into force: 1990. [www2.ohchr.org/english/law/crc.htm](http://www2.ohchr.org/english/law/crc.htm)
- 35 For further discussion, see *Policy Brief: Criminalization of HIV Transmission*, (2008). UNAIDS and UNDP. Available online at [data.unaids.org/pub/BaseDocument/2008/20080731\\_jc1513\\_policy\\_criminalization\\_en.pdf](http://data.unaids.org/pub/BaseDocument/2008/20080731_jc1513_policy_criminalization_en.pdf)
- 36 Mosher, W.D., Chandra, A. & Jones, J. (2005). Sexual Behavior and Selected Health Measures: Men and Women 15-44 Years of Age, United States, 2002. *Advance Data From Vital and Health Statistics*, 362, United States Centers for Disease Control and Prevention. [www.cdc.gov/nchs/data/ad/ad362.pdf](http://www.cdc.gov/nchs/data/ad/ad362.pdf); Leichter, J.S. et al. (2007). Prevalence and correlates of heterosexual anal and oral sex in adolescents and adults in the United States. *Journal of Infectious Disease*, 196(12), 1852-1859; Cáceres, C.F. et al., (1997). Young people and the structure of sexual risks in Lima, *AIDS*, 11(suppl. 1), S67-77; Ramjee, G. & Gouws, E. (2002). Prevalence of HIV among truck drivers visiting sex workers in KwaZulu-Natal, South Africa. *Sexually Transmitted Diseases*, 29, 44-49.
- 37 *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version*. (2006). Office of the UN High Commissioner for Human Rights and Joint United Nations Programme on HIV/AIDS. Available online at [data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf)
- 38 As noted above, however, some antiretroviral drugs may interact with some oral contraceptives, potentially affecting the effectiveness of either or both medications. Adjusting dosage, changing to another contraceptive or using condoms can address this problem.
- 39 Stephenson, J.M. & Griffioen A. (1996). The effect of HIV diagnosis on reproductive experience. Study Group for the Medical Research Council Collaborative Study of Women with HIV. *AIDS*, 10(14), 1683-1687.
- 40 *The World's Abortion Laws*. (2008). Center for Reproductive Rights. Available online at [reproductiverights.org/sites/crr.civicactions.net/files/pub\\_fac\\_abortionlaws2008.pdf](http://reproductiverights.org/sites/crr.civicactions.net/files/pub_fac_abortionlaws2008.pdf)
- 41 *HIV/AIDS: Reproductive Rights on the Line*. (2002). New York, Center for Reproductive Rights. [www.reproductiverights.org/pdf/bp\\_HIV\\_rroline.pdf](http://www.reproductiverights.org/pdf/bp_HIV_rroline.pdf); *AIDS Discrimination in Asia*. (2004). Bangkok, Asia Pacific Network of People living with HIV/AIDS. [www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf](http://www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf); *Sexual and Reproductive Health Needs of Women and Adolescent Girls Living with HIV: Research Report on Qualitative Findings from Brazil, Ethiopia and the Ukraine*. (2006). New York, EngenderHealth/UNFPA. [www.unfpa.org/upload/lib\\_pub\\_file/619\\_filename\\_srh-of-hiv-positive-women.pdf](http://www.unfpa.org/upload/lib_pub_file/619_filename_srh-of-hiv-positive-women.pdf)
- 42 Article 16. *Universal Declaration of Human Rights*. (1948). Paris, United Nations General Assembly. [www.unhchr.ch/udhr/lang/eng.htm](http://www.unhchr.ch/udhr/lang/eng.htm); Guideline 5: Antidiscrimination and protective laws.



- In *International Guidelines on HIV/AIDS and Human Rights*, 2006 Consolidated Version. (2006). Geneva, UNHCHR and UNAIDS. [data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf).
- 43 Trials being carried out in Kisumu, Kenya, and Rakai District, Uganda have revealed at least a 53% and 51% reduction in risk of acquiring HIV infection, respectively. These results support findings published in 2005 from the South Africa Orange Farm Intervention Trial, sponsored by the French National Agency for Research on AIDS, which demonstrated at least a 60% reduction in HIV infection among men who were circumcised. Bailey, R.C., et al. (2007). Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial. *The Lancet*, 369, 643-656. [www.thelancet.com/journals/lancet/article/PIIS0140673607603122/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140673607603122/fulltext);
- Gray, R.H., et al. (2007). Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial, *The Lancet*, 369, 657-666. [www.thelancet.com/journals/lancet/article/PIIS0140673607603134/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140673607603134/fulltext); Avert, B, et al. Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: the ANRS 1265 Trial. (2005). *PLoS Medicine*, 2(11), e298. [medicine.plosjournals.org/perlserv/?request=get-document&doi=10.1371%2Fjournal.pmed.0020298](http://medicine.plosjournals.org/perlserv/?request=get-document&doi=10.1371%2Fjournal.pmed.0020298).
- 44 *New Data on Male Circumcision and HIV Prevention: Policy and Programme Implications*. (2007). Geneva, WHO and UNAIDS. [data.unaids.org/pub/Report/2007/mc\\_recommendations\\_en.pdf](http://data.unaids.org/pub/Report/2007/mc_recommendations_en.pdf).
- 45 *Safe, Voluntary, Informed Male Circumcision and Comprehensive HIV Prevention Programming: Guidance for decision-makers on human rights, ethical and legal considerations*. (2008). UNAIDS. Available online at [data.unaids.org/pub/Report/2008/jc1552\\_circumcision\\_en.pdf](http://data.unaids.org/pub/Report/2008/jc1552_circumcision_en.pdf)
- 46 Jenkins, C., et al. (2006). *Violence and Exposure to HIV Among Sex Workers in Phnom Penh, Cambodia*. Washington, DC, Policy Project. [www.researchforsexwork.org/downloads/Jenkins-CambodiaFinal.pdf](http://www.researchforsexwork.org/downloads/Jenkins-CambodiaFinal.pdf)
- 47 *2006 Report on the Global AIDS Epidemic*. (2006). Geneva, UNAIDS. [www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/default.asp](http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/default.asp)
- 48 Available online at [www.yogyakartaprinciples.org](http://www.yogyakartaprinciples.org)
- 49 Sanders, D. (2007). *Human rights and sexual orientation in international law*. Brussels, International Lesbian and Gay Association. [www.ilga.org/news\\_results.asp?LanguageID=1&FileCategory=7&ZoneID=7&FileID=1078](http://www.ilga.org/news_results.asp?LanguageID=1&FileCategory=7&ZoneID=7&FileID=1078).
- 50 *Malawi: HIV/AIDS project reaches out to prisoners*. UN Office for the Coordination of Humanitarian Affairs. IRINNews. Retrieved November 13, 2002. [www.irinnews.org/report.asp?ReportID=30904](http://www.irinnews.org/report.asp?ReportID=30904)
- 51 *Trends in Total Migrant Stock: The 2005 Revision: CD-ROM Documentation*. (2006). New York, United Nations Department of Economic and Social Affairs. [www.un.org/esa/population/publications/migration/UN\\_Migrant\\_Stock\\_Documentation\\_2005.pdf](http://www.un.org/esa/population/publications/migration/UN_Migrant_Stock_Documentation_2005.pdf).
- 52 For further discussion, see the *Report of the International Task Team on HIV-related Travel Restrictions: Findings and Recommendations* (2008). Available on-line at [data.unaids.org/pub/Report/2008/20081017\\_itt\\_report\\_travel\\_restrictions\\_en.pdf](http://data.unaids.org/pub/Report/2008/20081017_itt_report_travel_restrictions_en.pdf). See also the three papers commissioned by the Task Team: *Mapping of restrictions on the entry, stay and residence of people living with HIV* ([data.unaids.org/pub/InformationNote/2008/20081027\\_crp5\\_mappingdocument\\_itt\\_final\\_en.pdf](http://data.unaids.org/pub/InformationNote/2008/20081027_crp5_mappingdocument_itt_final_en.pdf)); *The impact of HIV-related restrictions on entry, stay and residence: personal narratives* ([data.unaids.org/pub/InformationNote/2008/20081027\\_crp6\\_personalnarratives\\_itt\\_final\\_en.pdf](http://data.unaids.org/pub/InformationNote/2008/20081027_crp6_personalnarratives_itt_final_en.pdf)); and *The impact of HIV-related restrictions on entry, stay and residence: an annotated bibliography* ([data.unaids.org/pub/InformationNote/2008/20081027\\_crp4\\_annotatedbiblio\\_itt\\_final\\_\\_en.pdf](http://data.unaids.org/pub/InformationNote/2008/20081027_crp4_annotatedbiblio_itt_final__en.pdf)).
- 53 See the *Report of the International Task Team on HIV-related Travel Restrictions*, pp. 19-20.
- 54 The special procedures of the United Nations Human Rights Council is one such example. Independent experts (often called 'Special Rapporteurs') appointed by the Council have a mandate to take up individual cases, including on health-related human rights issues. For more information, see [www2.ohchr.org/english/bodies/chr/special/communications.htm](http://www2.ohchr.org/english/bodies/chr/special/communications.htm)
- 55 For a collection of national HIV-related jurisprudence, see *Courting Rights: Case Studies in Litigating the Human Rights of People Living with HIV*. (2006). UNAIDS and Canadian HIV/AIDS Legal Network. Available online at [data.unaids.org/Publications/IRC-pub07/jc189-courtingrights\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc189-courtingrights_en.pdf)
- 56 For more information, see [www.stigmaindex.org](http://www.stigmaindex.org)
- 57 For more information, see [www.unfpa.org/hiv/reportcard.htm](http://www.unfpa.org/hiv/reportcard.htm)
- 58 For more information, see [www.aidstreatmentaccess.org](http://www.aidstreatmentaccess.org)
- Chapter 4**
- 59 Paxton, S. (2002). The impact of utilizing HIV-positive speakers in AIDS education. *AIDS Education and Prevention*, 14(4), 282-294.
- 60 For examples of strategies and programmes, see *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes – A resource for national stakeholders in the HIV response*. (2007). UNAIDS. Available online at [data.unaids.org](http://data.unaids.org)

- unaids.org/pub/Report/2008/jc1420-stigmadiscrimi\_en.pdf
- 61 Merkel, J. (2006). *Advocacy Tool – The Sexual And Reproductive Rights And Health Of HIV Positive Women in South Africa*. London, International Community of Women Living with HIV/AIDS. [www.icw.org/files/SRHRs%20South%20Africa%20%2006.doc](http://www.icw.org/files/SRHRs%20South%20Africa%20%2006.doc); Duvvury, N., Prasad, N. & Kishore N. (2006). *HIV & AIDS – Stigma and Violence Reduction Intervention Manual*. Washington, DC, International Center for Research on Women. [www.icrw.org/docs/2006\\_SVRI-Manual.pdf](http://www.icrw.org/docs/2006_SVRI-Manual.pdf).
- 62 See *Policy Brief: HIV and Disability*. (2009, forthcoming), UNAIDS, WHO and OHCHR.
- 63 For more on this issue, see *Policy Brief: HIV, Food Security and Nutrition*. (2008). World Food Programme, WHO and UNAIDS. Available online at [data.unaids.org/pub/Manual/2008/jc1515a\\_policybrief\\_nutrition\\_en.pdf](http://data.unaids.org/pub/Manual/2008/jc1515a_policybrief_nutrition_en.pdf)
- 64 *Declaration of the Paris AIDS Summit*, 1 December 1994. [data.unaids.org/pub/ExternalDocument/2007/theparisdeclaration\\_en.pdf](http://data.unaids.org/pub/ExternalDocument/2007/theparisdeclaration_en.pdf)
- 65 Paxton, S. (2002). The impact of utilizing HIV-positive speakers in AIDS education. *AIDS Education and Prevention*, 14(4), 282-294; Takai, A., et al. (1998). Correlation between history of contact with people living with HIV/AIDS (PWAs) and tolerant attitudes toward HIV/AIDS and PWAs in rural Thailand. *International Journal of STD and AIDS*, 9(8), 482-484.
- 66 Available online at [www.hivcode.org](http://www.hivcode.org)
- 67 *Sexual and Reproductive Health Needs of Women and Adolescent Girls Living with HIV: Research Report on Qualitative Findings from Brazil, Ethiopia and the Ukraine*. (2006). New York, EngenderHealth and UNFPA. [www.unfpa.org/upload/lib\\_pub\\_file/619\\_filename\\_srh-of-hiv-positive-women.pdf](http://www.unfpa.org/upload/lib_pub_file/619_filename_srh-of-hiv-positive-women.pdf); *Reducing Stigma and Discrimination Related to HIV/AIDS: Training for Health Care Workers*. (2004). New York, EngenderHealth. [www.engenderhealth.org/pubs/hiv-aids-sti/reducing-stigma.php](http://www.engenderhealth.org/pubs/hiv-aids-sti/reducing-stigma.php).
- 68 For more information see [www.stigmaindex.org](http://www.stigmaindex.org).
- 69 *AIDS Discrimination in Asia*. (2004). Bangkok, Asia Pacific Network of People living with HIV/AIDS. [www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf](http://www.apnplus.org/document/AIDS%20Discrimination%20in%20Asia.pdf)
- 70 For a partial list of possible research areas, see box ‘Advocacy Recommendations’ in Chapter 4.
- 71 De Bruyn, M. (2006). *Fulfilling reproductive rights for women affected by HIV/AIDS. A tool for monitoring progress toward three Millennium Development Goals*. Updated version. Chapel Hill, NC, Ipas. [www.icw.org/files/Ipas%20MDG-HIV-RH%20monitoring%20tool%2008-06.pdf](http://www.icw.org/files/Ipas%20MDG-HIV-RH%20monitoring%20tool%2008-06.pdf); De Bruyn, M. (2006). ‘There’s nothing you could do if your rights were being violated.’ *Monitoring Millennium Development Goals in relation to HIV-positive women’s rights*. Chapel Hill, NC, Ipas. [www.icw.org/files/Ipas%20MDG-HIV-RH%20monitoring%20tool%2008-06.pdf](http://www.icw.org/files/Ipas%20MDG-HIV-RH%20monitoring%20tool%2008-06.pdf).
- 72 For more information, see [www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx](http://www.ohchr.org/EN/HRBodies/Pages/HumanRightsBodies.aspx)
- 73 To search recommendations of all the human rights treaty bodies (including by country and keyword – e.g., ‘HIV’), see [www.universalhumanrightsindex.org](http://www.universalhumanrightsindex.org)
- 74 *Parliamentarians for Women’s Health. Listening to HIV-positive women. In Financing Gender Equality 2007: Commonwealth Perspectives*. (2007). London, Commonwealth Secretariat, pp. 72-75. [www.icw.org/files/Listening%20to%20HIV%20positive%20Women\\_Parliamentarians%20for%20Womens%20Health.pdf](http://www.icw.org/files/Listening%20to%20HIV%20positive%20Women_Parliamentarians%20for%20Womens%20Health.pdf)

## PHOTO CREDITS

- Page 8 – A. UNAIDS/B. Press: Toco, Trinidad. Communication activity; B. Pradeep Tewari, Courtesy of Photoshare: An HIV positive man, woman, and girl meet with a doctor and a female advocate in Chandigarh, India; C. UNAIDS/C. Sattlberger: HIV positive young mother with child, Guatemala city, Guatemala. D. UNAIDS/A.Gutman: Baylor's home, care center for PLHIV in Mozambique; E. UNAIDS/S. Noorani : Scenes from the poor brothel district known as Phum Thmev (New Village) Sihanoukville Province. Cambodia; F. UNAIDS/L.Taylor : Schelikovo festival Kostroma district Russia. Young People interacting, laughing, singing, dancing, drinking and being merry; G. UNAIDS/G.Pirozzi: Manila, Philippines; H. UNAIDS/L.Taylor: Father and son in Bibianiha community near Accra, Ghana.
- Page 11 – Pradeep Tewari, Courtesy of Photoshare: Puja Thakur, an HIV positive woman from Chandigarh, India, speaks about HIV/AIDS, reproductive health, and sexual rights of women to government school students in the village of Kaimbwala near Chandigarh.
- Page 14 – UNAIDS/O.O'Hanlon: Continuum of Care project provides facility and community based care for people living with HIV from 20 referral hospitals in Cambodia.
- Page 17 – UNAIDS/P.Virot: Mali
- Page 18 – UNAIDS/A.Gutman: St. Gabriel Mission Hospital in Lilongwe, Malawi, 2006. This hospital has PMTCT as well as Voluntary Counseling and Testing services.
- Page 20 – UNAIDS/B.Neeleman: A small group of street children in Maputo, Mozambique, inform pedestrians about the risks of unsafe sex and demonstrate the proper use of condoms to prevent HIV infection.
- Page 22 – UNAIDS/G.Pirozzi: Kibera Community Centre, Kenya. Florence (27) and Saul (21), both HIV positive are peer educators at the centre.
- Page 25 – UNAIDS/G.Pirozzi: Traditional birth attendants talking to a pregnant woman, Cairo, Egypt. Traditional birth attendants receive information on HIV/AIDS during their training.
- Page 27 – IRIN/G. Cranston: Sabila, 15 has been repeatedly mistreated by her slave master, often being raped. She was born into slavery. She is one of among 43,000 people enslaved in Niger, West Africa. Most are physically and often sexually abused.
- Page 28 – Sisca J. Esperanza, Courtesy of Photoshare: Adolescents from the community gather at HI roundabout in Jakarta, Indonesia in support of human rights and gay rights.
- Page 29 – UNAIDS/R.Bowman: United Nations building in New York with Red Ribbon during UNGASS.
- Page 32 – IRIN/Allan Gichigi: Local women line up to get tested for HIV at the voluntary counseling centre, Gongoni health centre, Malindi, Kenya, July 2007.
- Page 33 – UNAIDS/K.Hesse: A newly wed couple get their wedding picture taken at the friendship bridge in Dandong, China.
- Page 35 – UNAIDS/S.Noorani: A commercial sex worker at Phum Thmev. Sihanoukville Province, Cambodia.
- Page 36 – IRIN/Tanvir Ahmed-Dirk: Drug-users on the roadside in Dhaka, capital of Bangladesh, February 2008. Some NGOs are distributing new syringes but many addicts still share with other users, heightening the risk of disease.
- Page 38 – IRIN/Hugo Rami: Two prisoners wait behind bars for a second chance of freedom by the court of appeals in the Democratic Republic of the Congo, May 2006. After years of civil war and decades of unrest, the country's infrastructure has almost completely broken down.
- Page 40 – UNAIDS/L.Taylor: World AIDS Day activities in Kiev, Ukraine
- Page 41 – IRIN/Sarah Mace: A group of HIV-positive march through Nairobi to protest at a proposed amendment that could hike the price of ARVs and other life-saving drugs, July 25 2006.
- Page 43 – UNAIDS/L.Gubb: PHAKAMA (Rise, Stand up) participative theater group plays a piece about rape and violence against women, and the dangers of its spreading HIV infection. South Africa.
- Page 44 – UNAIDS/L.Taylor: Sex workers waving down trucks. Russia.
- Page 46 – GNP+: Young people discussing during the GNP+ and UNAIDS Technical Consultation on Positive Health, Dignity and Prevention in Tunisia, April 2009.
- Page 51 – A. UNAIDS/L.Gubb: Tzaneen area, South Africa. Traditionally dressed Shangaan women from rural Tzaneen, many of them widowed by HIV/AIDS, or infected themselves, dance and sing songs they've composed about HIV at a meeting of their support group; B. UNAIDS/O.O'Hanlon: Phnom Penh has more than 5000 brothel-based direct sex workers and indirect sex workers who sell sex to supplement their income. Chhouk Sar is a support group for HIV positive sex workers, which is run by HIV positive sex workers (or former sex workers). Cambodia; C. UNAIDS/C. Sattlberger: Project OASIS member handling out condoms to a transvestite CSW. Guatemala City; D. UNAIDS/A.Gutman: Baylor's home, care center for PLHIV in Mozambique; E WHO/A.Waak: In the health clinic of Centro Velho, in Santos, Brazil, a team of health workers, dentists and social workers offer medical advice, testing and care to people with HIV and AIDS; F UNAIDS/P.Virot: Morocco; G. Rick Maiman/David and Lucile Packard Foundation, Courtesy of Photoshare: Teenage boys listen outside the window of a sex education class in one of Mexico City's poorest areas; H. UNAIDS/B. Press: Trinidad. Vender in Market selling fruits.







