

# POSITIVE HEALTH, DIGNITY AND PREVENTION

## A POLICY FRAMEWORK



## ACKNOWLEDGEMENTS

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## ACRONYMS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>APN+</b>	Asia Pacific Network of People Living with HIV
<b>ARASA</b>	AIDS and Rights Alliance of Southern Africa
<b>ART</b>	Antiretroviral Therapy
<b>ARV</b>	Antiretroviral
<b>CBO</b>	Community-based Organisation
<b>CCM</b>	Country Coordinating Mechanism
<b>CDC</b>	(United States) Centres for Disease Control and Prevention
<b>CHMT</b>	Community Health Media Trust
<b>CSS</b>	Community Systems Strengthening
<b>DAH</b>	Deutsche AIDS-Hilfe
<b>EATG</b>	European AIDS Treatment Group
<b>EKAF</b>	Swiss Federal AIDS Commission
<b>GIPA</b>	Greater Involvement of People Living with HIV
<b>GMFA</b>	Formerly Gay Men Fighting AIDS
<b>GNP+</b>	Global Network of People Living with HIV
<b>HIV</b>	Human Immunodeficiency Virus
<b>IAS</b>	International AIDS Society
<b>ICASO</b>	International Council of AIDS Service Organizations
<b>ICW</b>	International Community of Women Living with HIV
<b>IPPF</b>	International Planned Parenthood Federation
<b>ITPC</b>	International Treatment Preparedness Coalition
<b>MERG</b>	UNAIDS Monitoring and Evaluation Reference Group
<b>NAPWA</b>	National Association of People living with AIDS
<b>NCPI</b>	National Composite Policy Index
<b>NGO</b>	Non-governmental Organisation
<b>OI</b>	Opportunistic Infection
<b>PEPFAR</b>	U.S. President's Emergency Plan for AIDS Relief
<b>SRHR</b>	Sexual and Reproductive Health and Rights
<b>STI</b>	Sexually Transmitted Infection
<b>TAC</b>	Treatment Action Campaign
<b>TB</b>	Tuberculosis
<b>TMAP</b>	Treatment Monitoring and Advocacy Project
<b>UN</b>	United Nations
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNDP</b>	United Nations Development Programme
<b>UNFPA</b>	United Nations Population Fund
<b>UNGASS</b>	United Nations General Assembly Special Session on HIV/AIDS
<b>VCT</b>	Voluntary Counselling and Testing
<b>WHO</b>	World Health Organization

## FOREWORD

Positive Health, Dignity and Prevention highlights the importance of placing the person living with HIV at the centre of managing their health and wellbeing. Among other things, this Framework takes us beyond the more limited concept of 'positive prevention' which focuses only on people living with HIV 'preventing' the transmission of HIV.

In contrast, Positive Health, Dignity and Prevention stresses the importance of addressing prevention and treatment simultaneously and holistically. It also emphasises the leadership roles of people living with HIV in responding to policy and legal barriers within the socio-cultural and legal contexts in which they live, and in driving the agenda forward toward better health and dignity.

Whilst acknowledging current work in the area of 'positive prevention' this Framework helps inform and expand on this work and provides further policy guidance in terms of understanding how to enhance and nurture the leadership of people living with HIV, as they define and guide existing programmes that allow them to live in dignity, maintain or improve their health, and make choices that have beneficial results for themselves and their partners, families, and communities. It will also ensure that people living with HIV feel they have ownership of the programmes and services that are focused towards them.

In considering the ongoing challenge of HIV prevention, people living with HIV should be recognised as a part of the solution—not a part of the 'problem'. The public health and human rights goal of preventing new HIV infections can only be achieved when the human, sexual, and reproductive rights of people living with HIV are protected and supported; when the broader health and dignity needs of people living with HIV are met; and when access to timely and uninterrupted treatment and care encourages greater uptake of confidential voluntary counselling and testing.

These important goals can be achieved with broad stakeholder commitment to this Framework. We hope that Positive Health, Dignity and Prevention will shape how governments, policymakers, programmers and international agencies work with people living with HIV: moving away from treating people living with HIV as passive targets of prevention messages towards recognising them as active participants in the global HIV response.

Kevin Moody  
International Coordinator and CEO, GNP+

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UNAIDS Executive Director

## EXECUTIVE SUMMARY

The primary goals of Positive Health, Dignity and Prevention are to improve the dignity, quality, and length of life of people living with HIV; which, if achieved will, in turn, have a beneficial impact on their partners, families, and communities, including reducing the likelihood of new infections.

Positive Health, Dignity and Prevention is not just a new name for the concept of HIV prevention for and by people living with HIV, formerly known as 'positive prevention'. Rather, Positive Health, Dignity and Prevention is built on a broader basis that includes improving and maintaining the dignity of the individual living with HIV, to support and enhance that individual's physical, mental, emotional and sexual health, and which, in turn, among other benefits, creates an enabling environment that will reduce the likelihood of new HIV infections.

Positive Health, Dignity and Prevention encompasses the full range of health and social-justice issues for people living with HIV, and espouses the fundamental principles that responsibility for HIV prevention should be shared, and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV.

By linking together the social, health, and prevention needs of the individual living with HIV within a human-rights framework, Positive Health, Dignity and Prevention results in a more efficient use of resources, with outcomes more responsive to the needs of people living with HIV and more beneficial for their partners, families, and communities. This Framework is the first step towards operationalising Positive Health, Dignity and Prevention. It should be seen as a living document that adapts to the evolving needs of people living with HIV and the policies and programmes that serve them.

Attaining the goal of Positive Health, Dignity and Prevention specifically requires promoting and affirming the empowerment of people living with HIV through the following objectives:

- Increasing access to, and understanding of, evidence-informed, human-rights-based policies and programmes that support individuals living with HIV to make choices that address their needs and allow them to live healthy lives free from stigma and discrimination.
- Scaling up and supporting existing HIV counselling, testing, care, support, treatment, and prevention programmes that are community owned and led, and increasing access to rights-based health services including sexual and reproductive health.
- Scaling-up and supporting literacy programmes in health, treatment, prevention, human rights and the law, and ensuring that human rights are promoted and implemented through relevant programmes and protections.
- Ensuring that undiagnosed and diagnosed people, along with their partners and communities, are included in HIV prevention programmes that highlight shared responsibilities regardless of known or perceived HIV status and have opportunities for, rather than barriers to, empowering themselves and their sexual partner(s).
- Scaling up and supporting social capital programmes that focus on community-driven, sustainable responses to HIV by investing in community development, networking, capacity-building, and resources for people living with HIV organizations and networks.

Operationalising Positive Health, Dignity and Prevention is not about creating new programmes, except where basic programmes currently do not exist. Rather, it is about using this new framework to create linkages among existing programmes and also taking them to scale, so that they are more efficient and more responsive to the needs of people living with HIV.

Individual programmatic elements will inevitably differ from setting to setting, as local needs and resources dictate, but fall under eight major component headings.

- **EMPOWERMENT**
- **GENDER EQUALITY**
- **HEALTH PROMOTION AND ACCESS**
- **HUMAN RIGHTS**
- **PREVENTING NEW INFECTIONS**
- **SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS**
- **SOCIAL AND ECONOMIC SUPPORT**
- **MEASURING IMPACT**

Nine action areas are recommended to move forward with the development of operational guidelines for Positive Health, Dignity and Prevention, with specific roles and responsibilities for GNP+, other networks of people living with HIV, civil society, the public and private sectors, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Secretariat and Cosponsors and donor agencies.

#### **1 ADVOCACY**

To increase the meaningful and broad-based mobilisation of people living with HIV in HIV prevention efforts and increase the capacity of organizations and networks of people living with HIV at global, regional, and country levels to participate as full, equal, and essential partners in the planning, implementation, monitoring, and evaluation of Positive Health, Dignity and Prevention.

#### **2 BUILDING EVIDENCE**

To evaluate existing policies and programmes for their readiness to be integrated into the Positive Health, Dignity and Prevention Framework; to provide evidence of existing good practice.

#### **3 DISSEMINATION**

To ensure the robust endorsement, adoption, and implementation of the Positive Health, Dignity and Prevention concept by key stakeholders at global, regional and country levels.

#### **4 POLICY DIALOGUE**

To agree on priority areas for implementation, including linkages between existing programmes, and to understand gaps in current policies relating to HIV prevention for people living with HIV.

#### **5 PLANNING**

To prepare for standard operational guidelines for Positive Health, Dignity and Prevention.

#### **6 IMPLEMENTATION**

To develop standard operational guidelines for Positive Health, Dignity and Prevention.

#### **7 INTEGRATION**

To integrate standard operational guidelines into national strategic frameworks, resources, plans, policies, and monitoring and evaluation systems.

#### **8 MONITORING AND EVALUATION**

To develop monitoring and evaluation indicators for implementation of Positive Health, Dignity and Prevention, including programme linkages; policy development; effectiveness in reducing new infections; and individual and population health outcomes.

#### **9 ADAPTATION AND IMPROVEMENT**

To adapt the Framework and operational guidelines in light of new findings from monitoring and evaluation as the epidemic changes, more evidence accumulates, and other changes occur (e.g. new prevention technologies, better understanding of treatment as prevention, changes enabling or disabling funding, policy and legal environments).



# Background

## **HIV PREVENTION AND PEOPLE LIVING WITH HIV**

Local, national, regional and global responses to the HIV epidemic have been often slow to respond to the myriad health, dignity and prevention needs of people living with HIV. This has been true in terms of providing universal access to counselling, confidential testing, treatment, care and support as well as providing enabling and supportive legal and policy environments for people living with, and communities affected by, HIV.

Furthermore, there have been significant shortcomings of HIV prevention approaches focusing on individuals living with HIV that have tended to treat them primarily as potential vectors of new infections, rather than as individuals with complex and competing needs and desires.

People living with HIV have always been powerful and passionate advocates for HIV prevention but relatively few policies and programmes have adequately supported people who have tested HIV-positive in their desire to prevent new HIV infections.

Rather, it has been erroneously assumed that once a person becomes aware of their HIV-positive status, that person automatically acquires the complex skills required for effective communication, decision-making and taking action around HIV transmission risk.

For example, disclosure of one's HIV-positive status is a process that requires skills and support to accomplish, and is particularly challenging without an enabling environment

free of stigma and discrimination. Similarly, using condoms correctly and consistently also requires skills (how to use, negotiation, communication), a favourable attitude toward condoms, equal power dynamics in relationships, and resources (access to male and female condoms and waterbased lubricant).

In addition, people living with HIV often have many social-support needs that may compete with their desire to prevent new infections. HIV transmission does not take place in a vacuum. Behaviours that may lead to HIV transmission are often the outcomes of underlying economic, social, and/or psychological issues, such as poverty, gender-based violence, and/or homophobia, and may also be the result of a desire for a family.

Oppressive and/or punitive social, legal and policy environments often discourage people from learning their status. In such environments those who do know their status are unable to disclose it with safety, and unable also to take up HIV prevention and treatment services safely—that is without a real risk of experiencing stigma, discrimination and/or the possibility of prosecution. Oppressive factors include: mandatory HIV testing or treatment; involuntary or mandatory disclosure; laws and prosecutions for non-disclosure, potential HIV exposure or non-intentional transmission; and/or laws and prosecutions for potentially HIV-related risk-taking behaviours such as injecting drug use, sex work and/or sex between men, and/or identities such as being lesbian, gay, bisexual, transgender, or intersex.

There are also important links between the health needs of a person living with HIV—related to timely access to antiretroviral therapy; preventing opportunistic infections and other illnesses; preventing premature death, and prolonging a productive, healthy life—and their ability to prevent new HIV infections.

Failing to recognise the significance of such health and dignity issues can result in oversimplified and medicalized HIV prevention programming that ignores the full spectrum of challenges shaping the prevention needs, abilities and incentives of people living with HIV.

However, preventing new HIV infections must be a goal for everyone regardless of a person's known or assumed HIV status or their proximity to the virus and its impact. A common misperception is that that most new HIV infections involve a person who is aware of being HIV-positive. But according to the most recently published data on people aware and unaware of their HIV status, the vast majority of people living with HIV worldwide—an estimated 80%–90%—have not yet been tested and are unaware of their HIV-positive status.<sup>[1]</sup>

The United States Centers for Disease Control (CDC) has found that people unaware they are living with HIV are more than twice as likely to engage in high-risk sex than those aware of their HIV-positive status<sup>[2]</sup> and have also estimated that up to 70% of new HIV infections are acquired from people who are undiagnosed.<sup>[3]</sup> These estimates were based on an assumption that three out of four people living with HIV were aware of their status. In settings where the number of people with undiagnosed HIV far outweigh the number with diagnosed HIV, it is likely that the vast majority of new HIV infections result from sex between individuals neither of whom are aware that one is already living with HIV.

Individuals most likely to be of public health concern—people unaware they are living with HIV—are much

more likely to come forward for counselling, testing, care, support, and treatment when safe, effective, and uninterrupted treatment is available, affordable and reliably accessible, and when people diagnosed HIV-positive are supported and protected by enabling legal and policy environments, and are not controlled, threatened, stigmatised, discriminated against, prosecuted or punished.

## **A NEW FRAMEWORK FOR HIV PREVENTION BY PEOPLE LIVING WITH HIV**

In April 2009, an international technical consultation on HIV prevention for people living with HIV took place in Tunisia. Participants—more than half of whom were living with HIV—represented networks of people living with HIV, civil society, government agencies, UNAIDS Secretariat and Cosponsors, international donors and development agencies.<sup>[4]</sup> It was agreed that the focus of current approaches was too limited and should be replaced by a broader, more holistic and interconnected human rights-based approach.

Participants agreed that policies and programmes that:

- are designed and implemented with the meaningful involvement of people living with HIV;
- treat people living with HIV humanely and with dignity;
- provide people with knowledge, skills, social and legal support; and
- focus on the holistic health and related needs of people living with HIV,

are more likely to be accepted and implemented, and will be more effective than existing programmes that narrowly focus on preventing new infections.

Such policies and programmes will also help to reduce HIV-related stigma and discrimination, resulting in numerous beneficial effects for people living with HIV (including those who are unaware of their status) and their partners, families, and communities.

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1 UNAIDS, *AIDS Epidemic Update 2009*, Geneva, 2009.

2 Marks, G., et al. "Meta-analysis of high-risk sexual behaviour in persons aware and unaware they are infected with HIV in the United States: implications for HIV prevention programs." *JAIDS*, 39(4): 446–53, 2005.

3 Marks, G., et al. "Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA." *AIDS* 20(10): 1447–50, 2006.

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4 GNP+/UNAIDS. *Technical Consultation Report: Positive Health, Dignity and Prevention*, April 2009.

## A NEW NAME FOR A NEW FRAMEWORK

As part of the shift towards a new health and human rights-centred approach, a new term has been introduced: Positive Health, Dignity and Prevention. Consultations undertaken by GNP+ and its partners have highlighted that just as the individual programmatic elements of Positive Health, Dignity and Prevention may change according to setting, so may the name need to be adapted when translated into local languages.

For example, consultations amongst representatives of people living with HIV in the Asia Pacific region preferred the term Positive Health as the concept of 'dignity' was not easily transferable in some Asia Pacific countries and the term 'prevention' continues to have connotations that people aware they are living with HIV have a greater burden of responsibility for HIV transmission.

Consultations amongst representatives of people living with HIV in French-speaking Africa also requested a review of the word 'dignity,' as the meaning of this word in English or French—as it relates to human rights—may not resonate for some people on the African continent.

In addition, consultations have noted that many existing programmes—and funding streams—are already termed 'Positive Prevention' or 'Prevention with Positives,' and there was concern that a new name may be confusing.

Developing a common language for the broader Framework of Positive Health, Dignity and Prevention is the ultimate goal, and it is especially important to consult people living with HIV about the term used to describe this Framework because the name affects how they feel about themselves and their ability to implement it into their own lives.

However, amongst those who are working to implement the Framework, its name is perhaps less important than its content. The main concern is that the Framework be incorporated into existing policies and programmes and that people living with HIV are placed at the centre of determining which policies and programmes support and enable them to live healthy lives and make healthy choices.

## WHO IS THIS FRAMEWORK FOR?

This Framework provides the broad concepts that represent the first steps towards operationalising Positive Health, Dignity and Prevention. It should be used to inform the development and implementation of operational guidelines that reflect linkages between a wide range of policies and programmes aimed at supporting and improving the health, dignity and prevention needs of people living with HIV.

One principle of the Framework is that the development, implementation, and monitoring and evaluation of all policies and programmes affecting people living with HIV should include—and ideally be led by—them. Therefore, the Framework should be especially useful for organizations and networks of people living with HIV in developing an advocacy strategy and encouraging the involvement of people living with HIV in all aspects of moving Positive Health, Dignity and Prevention forward.

This Framework should also be a useful tool to guide the work of everyone involved in policies and programmes that seek to support and improve the health and dignity of people living with HIV, as well as those that are focused on preventing new infections (such as wider civil society; the public and private sectors, including the health and education sectors; and donor, multilateral, and UN-system agencies including UNAIDS.)<sup>5</sup>

<sup>5</sup> Positive Health, Dignity and Prevention is already an integral part of reducing sexual transmission of HIV in the UNAIDS Outcome Framework, 2009-11.



**WE ARE MORE THAN  
PATIENTS**

**WE WILL  
NOT BE TREATED  
AS VECTORS OF TRANSMISSION**

**WE ARE  
ALL RESPONSIBLE  
FOR HIV PREVENTION**

**WE HAVE  
NEEDS AND DESIRES  
TO BE FULLFILLED**

# Guiding principles and values

## 1 'WE ARE MORE THAN PATIENTS.'

People living with HIV are leaders in the design, programming, implementation, research, monitoring and evaluation of all programmes and policies affecting us.

People living with HIV have a great deal of knowledge, experience and insight into the issues that are important for them and for responding to the epidemic effectively. If the health, dignity and prevention needs of people living with HIV are to be adequately addressed, they must be meaningfully involved in all aspects of policies and programmes that impact them.

## 2 'WE WILL NOT BE TREATED AS VECTORS OF TRANSMISSION.'

A human rights approach is the foundation of Positive Health, Dignity and Prevention.<sup>[6]</sup>

People living with HIV strive for policies and programmes that do not oppress, manage, control abuse or criminalize them. Positive Health, Dignity and Prevention requires a human-rights framework (including rights-based approaches to HIV programming) supported by protective laws to: ensure non-discrimination; reduce stigma; provide access to justice; and change harmful gender norms. Such policies and programmes must enable people living with HIV to protect themselves and others—not through fear but through empowerment, and with dignity.

<sup>6</sup> See also, Strategic Direction 3: Advance human rights and gender equality for the HIV response, UNAIDS. Getting to Zero: 2011-15 Strategy, 2010.

## 3 'WE ARE ALL RESPONSIBLE FOR HIV PREVENTION.'

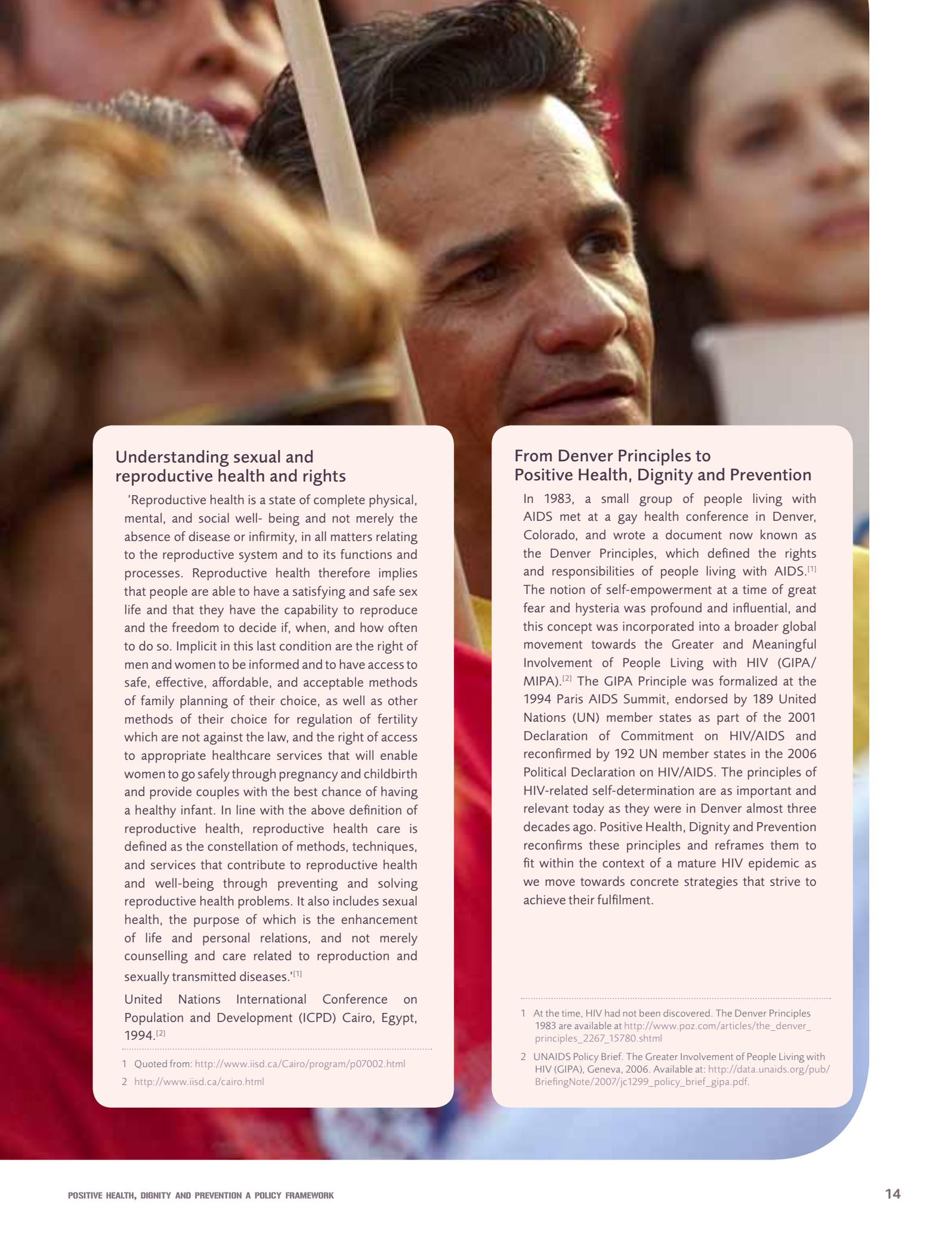
Preventing new HIV infections is the shared responsibility of everyone irrespective of HIV status.

Positive Health, Dignity and Prevention is about including people living with HIV in all aspects of HIV prevention. It rejects the notion that people living with HIV are solely responsible for the health of others they interact with. It also acknowledges and addresses HIV-related stigma and other social determinants of health that impact the vulnerability of those affected. It promotes supportive policies and programmes that help empower individuals to take responsibility for their own health and well-being. By doing so, this will have beneficial impact on partners, families and communities.

## 4 'WE HAVE NEEDS AND DESIRES TO BE FULFILLED.'

Sexual and reproductive health and rights<sup>[7]</sup> must be recognised and exercised by everyone regardless of HIV status.

<sup>7</sup> Sexual rights are a component of human rights. Sexual rights are constituted by a set of entitlements related to sexuality that emanate from the rights to freedom, equality, privacy, autonomy, integrity and dignity of all people. See: IPPF. Sexual Rights: an IPPF declaration, 2008.



## Understanding sexual and reproductive health and rights

'Reproductive health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when, and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable, and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate healthcare services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant. In line with the above definition of reproductive health, reproductive health care is defined as the constellation of methods, techniques, and services that contribute to reproductive health and well-being through preventing and solving reproductive health problems. It also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases.'<sup>[1]</sup>

United Nations International Conference on Population and Development (ICPD) Cairo, Egypt, 1994.<sup>[2]</sup>

1 Quoted from: <http://www.iisd.ca/Cairo/program/p07002.html>

2 <http://www.iisd.ca/cairo.html>

## From Denver Principles to Positive Health, Dignity and Prevention

In 1983, a small group of people living with AIDS met at a gay health conference in Denver, Colorado, and wrote a document now known as the Denver Principles, which defined the rights and responsibilities of people living with AIDS.<sup>[1]</sup> The notion of self-empowerment at a time of great fear and hysteria was profound and influential, and this concept was incorporated into a broader global movement towards the Greater and Meaningful Involvement of People Living with HIV (GIPA/MIPA).<sup>[2]</sup> The GIPA Principle was formalized at the 1994 Paris AIDS Summit, endorsed by 189 United Nations (UN) member states as part of the 2001 Declaration of Commitment on HIV/AIDS and reconfirmed by 192 UN member states in the 2006 Political Declaration on HIV/AIDS. The principles of HIV-related self-determination are as important and relevant today as they were in Denver almost three decades ago. Positive Health, Dignity and Prevention reconfirms these principles and reframes them to fit within the context of a mature HIV epidemic as we move towards concrete strategies that strive to achieve their fulfilment.

1 At the time, HIV had not been discovered. The Denver Principles 1983 are available at [http://www.poz.com/articles/the\\_denver\\_principles\\_2267\\_15780.shtml](http://www.poz.com/articles/the_denver_principles_2267_15780.shtml)

2 UNAIDS Policy Brief. The Greater Involvement of People Living with HIV (GIPA), Geneva, 2006. Available at: [http://data.unaids.org/pub/BriefingNote/2007/jc1299\\_policy\\_brief\\_gipa.pdf](http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf).

Following diagnosis, people living with HIV continue to have the same needs and desires for intimacy, sexual activity, family, and community as before. Positive Health, Dignity and Prevention is about creating the conditions for people living with HIV and their sexual partners to be free to make informed choices regarding whether and how to be sexually active and fulfilled and whether and how to conceive and enjoy a family.

## 5 VALUES

Positive Health, Dignity and Prevention can only be achieved through the following points:

- **A supportive and protective legal and policy environment that aims for a world free of HIV-related stigma and discrimination.**
- **A focus on improving and maintaining the health and well-being of people living with HIV, which, in turn, contributes to the health and well-being of their partners, families and communities.**
- **The promotion of holistic health and wellness, including universal, equitable access to voluntary HIV counselling, confidential testing, care and support and timely access to voluntary treatment and monitoring.**
- **Addressing a range of factors that undermine health and dignity, including: poverty and food insecurity; lack of mental and psychosocial support; lack of educational opportunity; social exclusion; gender inequality; and stigma and discrimination based on HIV-positive status, behaviours such as injecting drug use, sex work and/or sex between men, and identities such as being lesbian, gay, bisexual, transgender or intersex.**
- **Responding to the needs of key populations,<sup>[8]</sup> including the particular and specific needs of young people and women, and through respectful programmes tailored to specific contexts and the diversity among people living with HIV.**

8 Key populations at higher risk of living with HIV due to their social or legal status and/or behaviour include: indigenous peoples, men who have sex with men, migrants, people who use drugs, prisoners, refugees, sexual minorities (including intersex and transgender people), sex workers, women, and young people.

## What is 'shared responsibility'?

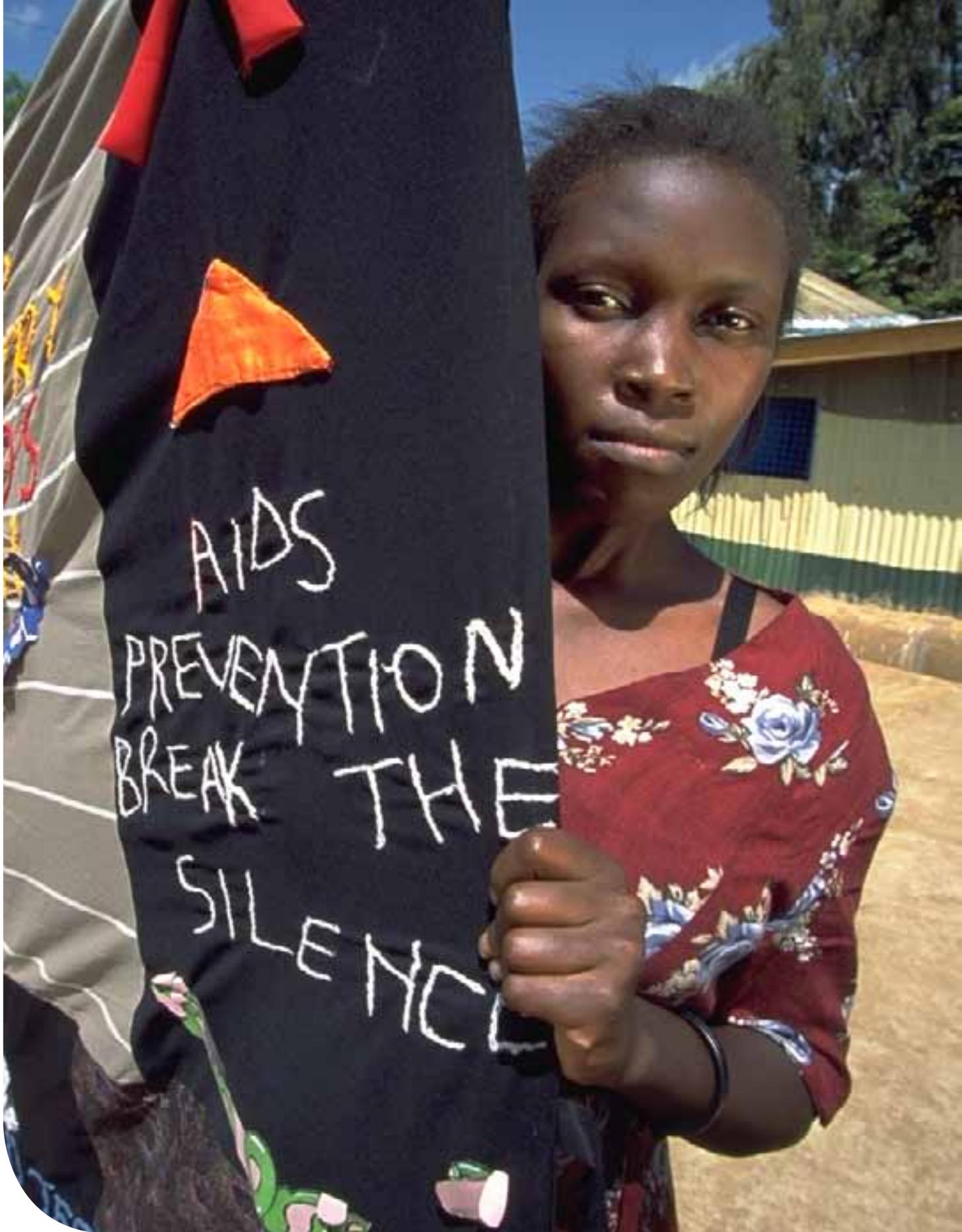
The 'prevention' in Positive Health, Dignity and Prevention rejects policies and programmes that focus exclusively on 'preventing onward transmission.' This is a potentially stigmatising phrase that can create the perception of one-sided responsibility for HIV prevention. It can also suggest that people living with HIV are scapegoats to blame when new HIV infections occur. 'Shared responsibility' for HIV prevention is about recognising the role that broader social determinants of health and dignity play in human and sexual behaviour. Firstly, it reinforces the concept that everyone is responsible for his or her health and should take steps to protect it. Thus, though people aware they are living with HIV know they have an ethical responsibility to avoid infecting another person, each individual shares the responsibility to avoid infection. Secondly, Positive Health, Dignity and Prevention creates an environment for HIV prevention beyond the individual—to include everyone regardless of their HIV status or proximity to the HIV epidemic. Sexual partners of people living with HIV, families, communities, civil society, the public and private sector, the media, donor and multilateral agencies such as the UN all share in the responsibility to prevent new HIV infections.

### Positive Health, Dignity and Prevention in practice:

#### Deconstructing 'shared responsibility' in Bolivia

In a four-day consultation (7 – 9 April 2010) co-organised by Redbol+ (Bolivian Network of People living with HIV/AIDS), GNP+, the Population Council, and UNAIDS, members of the Redbol+ steering committee explored the new concept of Positive Health, Dignity and Prevention and its implications for advocacy in Bolivia. Redbol+ steering committee members adapted an evidence-gathering methodology, which will be used for a study with 360 people living with HIV in Bolivia. With the support of the Ministry of Health, interviews will be conducted through support groups and within treatment and care centres. Findings from the survey will help inform Redbol+'s advocacy to amend Law Number 3729 (which stipulates disclosure to sexual partners and healthcare professionals<sup>[1]</sup> but which also has many protective provisions for funding for HIV treatment, care, and prevention), and within other national, regional, and international processes.

1 See the Global Criminalization Scan website further information on HIV and criminal and public health laws in Bolivia.



# Goals and objectives

*There is an urgent need to ensure that the goals of Positive Health, Dignity and Prevention are achieved and get the same attention as access to treatment. The right to health and other human rights should be protected and fulfilled, particularly when there has been an expansion of punitive laws, policies and practices which violate human rights, increase stigma and discrimination, and homophobia, and also have implications for HIV funding cuts.*

*Vuyiseka Dubula,  
General Secretary, Treatment Action Campaign, South Africa.*

The primary goals of Positive Health, Dignity and Prevention are to improve the dignity, quality and length of life of people living with HIV; which, in turn, will have a beneficial impact on partners, families, and communities, including reducing the likelihood of new infections.

Specifically, this requires promoting and affirming the empowerment of people living with HIV through the following objectives.

- 1 Increasing access to, and understanding of, evidence-informed, human-rights-based policies and programmes that support individuals living with HIV to make choices that address their needs and allow them to live healthy lives free from stigma and discrimination.**

## **Positive Health, Dignity and Prevention in practice: The 'Swiss Statement'**

In January 2008, the Swiss Federal AIDS Commission (EKAF), part of the Swiss Federal Office of Public Health, issued an evidence-informed consensus statement aimed at clinicians in Switzerland regarding the impact of antiretroviral therapy on individual infectiousness and under what specific circumstances antiretroviral therapy alone may be relied on as an HIV prevention tool.<sup>[1]</sup> EKAF considered the statement to be unique to the situation in Switzerland, where access to antiretroviral therapy and viral load testing is universal; where resources allow for individual HIV prevention counselling for people living with HIV; but where the legal framework punished people living with HIV for their HIV-negative partner's informed decision to have unprotected sex. Following this statement, EKAF worked closely with the Swiss AIDS Federation (AIDS-Hilfe Schweiz) to produce guidance for individuals<sup>[2]</sup> leading to policies and programmes that increased sexual and reproductive health choices for people living with HIV, and also worked with policymakers and prosecutors to help improve.

1 Vernazza, P., et al. 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 (5), 2008. [English translation. (including translator's affidavit)] HIV-positive individuals not suffering from any other STD and adhering to an effective antiretroviral treatment do not transmit HIV sexually.]

2 Swiss AIDS Federation. Advice Manual: Doing without condoms during potent ART. 2008.

**2** Scaling-up and supporting existing HIV counselling and testing, care, support, treatment, and prevention programmes that are community owned and led, and increasing access to rights-based health services including sexual and reproductive health.

**3** Scaling-up and supporting literacy programmes in health, treatment, prevention, human rights and the law and ensuring that human rights are promoted and implemented through relevant programmes and protections.

**Positive Health, Dignity and Prevention in practice:**

**AIDS Care China<sup>[1]</sup>**

AIDS Care China is a nongovernmental organization that delivers around 30 percent of all antiretroviral therapy to people living with HIV in China. An educational programme is offered at a community service centre situated next door to the HIV clinic. The two sites coordinate their work by sharing patient information linked via computer. Two full-time peer counsellors—one of whom is living with HIV—sited within the community service centre provide information and interventions tailored to the individual. AIDS Care's Positive Health, Dignity and Prevention programme is built on four building blocks: self-education; treatment literacy; self-esteem, and preventing illness.<sup>[2]</sup>

1 <http://www.aidscareschina.org/english/about.asp>

2 GNP+/UNAIDS. Technical Consultation Report: Positive Health, Dignity and Prevention, April 2009.

**Positive Health, Dignity and Prevention in practice:**

**People living with HIV ownership of treatment and legal literacy in Southern Africa**

Three South African civil society organizations led by people living with HIV—AIDS and Rights Alliance of Southern Africa (ARASA),<sup>[1]</sup> Community Health Media Trust (CHMT),<sup>[2]</sup> and Treatment Action Campaign (TAC)<sup>[3]</sup>—have been at the forefront of providing treatment and legal literacy for the region. ARASA, CHMT, and TAC's treatment literacy programmes have empowered people living with HIV to understand the science, treatment, side-effects, and guidelines so that they are empowered to become more responsible for their own care and will demand their rights when proper care is not available to them. In addition, ARASA's HIV/AIDS and Human Rights Advocacy and Training Resource Manual provides people living with HIV and those advocating on their behalf with information and ideas on how to strengthen a rights-based response to HIV in their own countries and the region.

1 <http://www.arasa.info/>

2 <http://www.beatit.co.za/home/index>

3 <http://www.tac.org.za/community/>



4 Ensuring that undiagnosed and diagnosed people living with HIV, along with their partners and communities, are included in HIV-prevention programmes that highlight shared responsibility regardless of known or perceived HIV status and have opportunities for, rather than barriers to, empowering themselves and their sexual partner(s).

5 Scaling up and supporting social capital programmes that focus on community-driven, sustainable responses to HIV by investing in community development, networking, capacity building and resources for people living with HIV organizations and networks. Operationalising Positive Health, Dignity and Prevention is not necessarily about creating new programmes, except where basic programmes currently do not exist. Rather, it is about using this new framework to create linkages among existing programmes, as well as taking them to scale, so that they are more efficient and more responsive to the needs of people living with HIV.

**Positive Health, Dignity and Prevention in practice:**

**GMFA's Responsibility Campaign**

Too many HIV prevention campaigns have only addressed people who are not living with HIV. Some have even treated people living with HIV as 'dangerous others.' For example, a 2010 HIV prevention campaign funded by the Illinois Department of Public Health produced a poster with the headline, "He's the one who could infect you." Following community protest, highlighting that it could demonise gay men living with HIV as 'monsters,' the campaign was quickly cancelled.<sup>[1]</sup> In contrast, GMFA (formerly Gay Men Fighting AIDS), the UK's leading gay men's health charity, involved gay men living with HIV through its Positive Campaign Group and produced a series of four posters in 2005 highlighting shared responsibility for HIV prevention that addressed all gay men regardless of their HIV status.<sup>[2]</sup>



1 Felion, M. "He's the One" Campaign Is Bait and Switch, May 11, 2010. <http://www.feastoffun.com/topics/health-wellness/2010/05/11/hes-the-1-is-way-off-mark/>

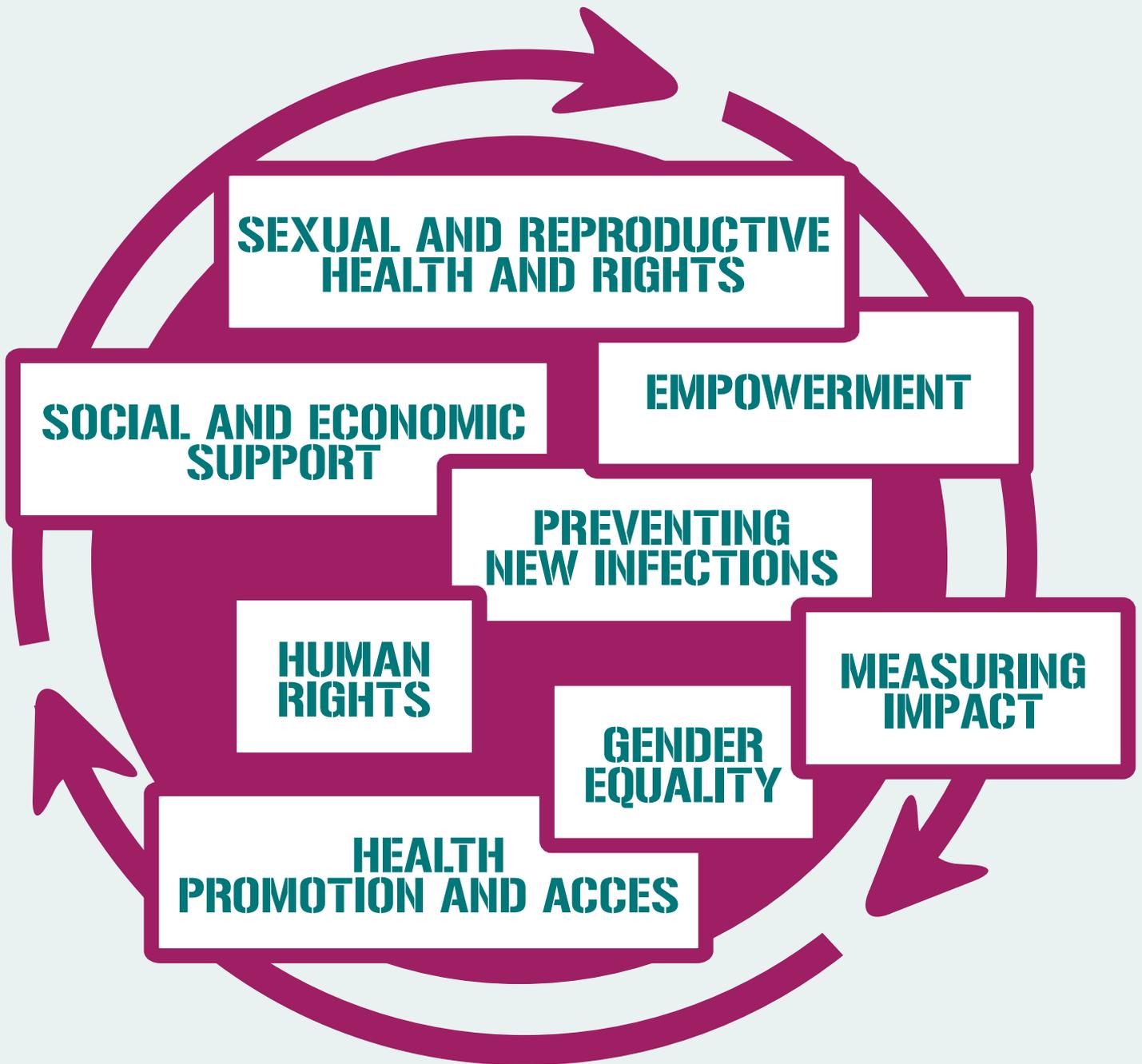
2 <http://www.gmfa.org.uk/londonservices/adcampaigns/gmfa#responsibility>

**Positive Health, Dignity and Prevention in practice:**

**Supporting Community Systems Strengthening**

Community systems strengthening (CSS) recognises the added value of investing in communities by focusing on capacity building and human and financial resources, with the aim of enabling communities and community actors to play a full and effective role in the HIV response and linking this with existing health and social welfare systems. Starting in Round 8, the Global Fund has been encouraging applicants to include measures to strengthen community systems relevant to in-country contexts on a routine basis in proposals for new and continuing funding. In 2010, the Global Fund and its partners developed a CSS framework to help develop the roles of key affected populations and communities, community organizations, networks, and public or private sector actors that work in partnership with civil society at community level in the design, delivery, monitoring, and evaluation of services and activities aimed at improving health outcomes.<sup>[1]</sup> Although a potentially useful mechanism, there remains a huge gap and need for other ways of scaling-up and supporting social capital programmes that focus on community-driven, sustainable responses to HIV.

1 [http://www.theglobalfund.org/documents/civilsociety/CSS\\_Framework.pdf](http://www.theglobalfund.org/documents/civilsociety/CSS_Framework.pdf)



# Programmatic components, elements and linkages

Individual programmatic elements will inevitably differ from setting to setting, as local needs and resources dictate, but fall under eight major component headings.

## **EMPOWERMENT**

## **GENDER EQUALITY**

## **HEALTH PROMOTION AND ACCESS**

## **HUMAN RIGHTS**

## **PREVENTING NEW INFECTIONS**

## **SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS**

## **SOCIAL AND ECONOMIC SUPPORT**

## **MEASURING IMPACT**

A non-exhaustive list, providing examples of programmatic elements under the main component headings of Positive Health, Dignity and Prevention, is given. Many elements achieve multiple programmatic aims and could also fit under other headings.

**Measuring impact** will be examined in greater detail in *Building Evidence and Measuring Impact, Progress, and Outcomes*.

## **EMPOWERMENT**

- Meaningful involvement of people living with HIV
  - Positive leadership
  - Participation in policy dialogue and advocacy
  - Mentoring of future leaders including women and young people living with HIV
  - Peer support groups

- Education and literacy
  - Treatment
  - Sexual health and comprehensive sexuality
  - Prevention of transmission
  - Reproductive health
  - Family planning
  - Legal and rights
  - Health education for living well (improving nutrition, ceasing smoking, limiting alcohol and drug use, increasing exercise), which helps provide information on health options
  - Building of self-esteem and confidence
  - Age-appropriate and HIV-specific sex and relationships education for children and adolescents born with HIV.
- Capacity building for organizations and networks of people living with HIV
  - Resources for networks and associations of people living with HIV
  - Social mobilisation and community engagement
  - Facilitation of networking opportunities
  - Linking to other social justice and development movements

## GENDER EQUALITY<sup>[9]</sup>

- Gender-based violence prevention and management
  - Health-provider training on sexuality, gender, stigma, discrimination and gender-based violence
  - Legal reform and enforcement of laws and mechanisms protecting people from gender-based violence
- Constructive engagement of men in reproductive and sexual health
- Appropriate health services for women living with HIV, including, but not limited to, prevention of vertical transmission of HIV
- Legal advocacy and activism for women's rights
  - Networking opportunities
- Legal advocacy and activism for rights for men who have sex with men, and for lesbian, gay, bisexual, transgender, and intersex people
  - Networking opportunities
- Economic empowerment of women
- Education
- Support for care-giving
- Social empowerment including equality in decision-making and negotiating skills

9 See WHO. Integrating gender into HIV/AIDS programmes in the health sector: tool to improve responsiveness to women's needs [http://www.searo.who.int/LinkFiles/Gender\\_Women\\_and\\_Health\\_gwh\\_hiv.pdf](http://www.searo.who.int/LinkFiles/Gender_Women_and_Health_gwh_hiv.pdf), Geneva, 2008.

## HEALTH PROMOTION AND ACCESS<sup>[10]</sup>

- Knowledge of HIV status under conditions of informed consent, confidentiality and good counselling
  - Community-based voluntary counselling and testing
  - Provider-initiated counselling and testing
- Treatment and care access, availability, sustainability, and quality assurance
  - Clinical monitoring
  - Availability and access of timely and appropriate<sup>[11]</sup> antiretroviral therapy
  - Antiretroviral therapy adherence support
  - Prevention of disease progression and further infections
  - Prophylaxis for tuberculosis (TB) and other opportunistic infections
  - Diagnosis and treatment for TB and other opportunistic infections
  - Diagnosis and treatment for Hepatitis C and other co-infections
  - Research and better understanding about the long-term effects of antiretroviral therapy and HIV, including of perinatally infected youth
  - Palliative care
  - Facilitated referral systems
- Psychosocial well-being services access, availability, sustainability, and quality assurance
  - Mental and emotional health services
  - Counselling services and support groups

10 See also WHO. Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings [http://www.who.int/entity/hiv/pub/prev\\_care/OMS\\_EPP\\_AFF\\_en.pdf](http://www.who.int/entity/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf). Geneva, 2008.

11 See UNAIDS. Treatment 2.0 - Is this the future of treatment? UNAIDS Outlook, July 2010.



## HUMAN RIGHTS

- Confidentiality of HIV-positive status
- Conditions for safe, voluntary, and beneficial disclosure
- Respect for individual autonomy
  - └ Choosing when, and if, to test, disclose, and/or initiate antiretroviral therapy
- Establishment of an enabling environment, including protective laws
  - └ Stigma and discrimination reduction
  - └ Support for advocacy and activism leading to legal and policy reform and implementation
  - └ A focus on shared responsibility for preventing new HIV infections, including removal of HIV-specific criminal laws

## PREVENTING NEW INFECTIONS

- Access and availability of tools and technologies that help prevent sexual HIV transmission
  - └ Male and female condoms and water-based lubricants
  - └ Male circumcision
  - └ Antiretroviral therapy
  - └ Post-exposure prophylaxis
  - └ New prevention technologies, such as pre-exposure prophylaxis and microbicides, as and when they become available
- Access and availability of services that help prevent vertical transmission
  - └ Primary prevention of HIV infection among women of childbearing age
  - └ Preventing unintended pregnancies among women living with HIV
  - └ Preventing HIV transmission from a woman living with HIV to her infant, including breast-feeding information and support
  - └ Providing appropriate treatment, care and support to mothers living with HIV and their children and families.
- Access to evidence-informed harm reduction for people who use drugs, including opiate substitution therapy
- Serodiscordant couples counselling (including partner and couples testing)
- Prevention, screening and treatment of sexually transmitted infections, including viral hepatitis
  - └ Human papillomavirus vaccination
  - └ Hepatitis A and hepatitis B vaccination

## SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

- Sexual health and well-being
  - └ Age-appropriate, comprehensive sexuality education, including a focus on the specific needs of adolescents born with HIV
  - └ Prevention and treatment of sexually transmitted infections, including viral hepatitis
  - └ Counselling and support for a satisfying sex life, including but not limited to improving libido, and treating sexual dysfunction
- Reproductive health
  - └ Maternal health
  - └ Family planning, including infertility and contraceptive services
  - └ Cervical, breast and other related cancer screening and management
  - └ Access to appropriate, safe and non-coerced termination services
- Sexual and reproductive health and rights advocacy and funding

## SOCIAL AND ECONOMIC SUPPORT

- Food and water security
- Social and economic support for caregivers
- Access to financial services
  - └ Support of productive linkages, including cooperatives
- Employment of people living with HIV
  - └ Further education and retraining opportunities for adults with HIV
  - └ Access to full education and employment opportunities for young people living with HIV
- Health and social protection for children and adolescents living with HIV

## Why Positive Health, Dignity and Prevention must include social and economic support

A multisectoral approach that includes economic security, housing, and social service needs is as necessary to support the Positive Health, Dignity and Prevention Framework as the more obvious health-related building blocks. A recent study by the International Treatment Preparedness Coalition (ITPC)<sup>[1]</sup> found that lack of access to adequate nutrition and the personal financial burden of those on treatment made it difficult for many to obtain—and remain in—necessary care. For example, in Kenya, where around half the Kenyan population lives on less than US\$ 1 a day, around 40% of people living with HIV who start antiretroviral therapy are no longer taking it after two years. The main reasons for not adhering are economic, since the bus fare to get to and from the clinic is unaffordable and competes with the ability to buy essentials, including food. 'I think more than 90% of the ART patients who come here cannot afford drugs when they are prescribed,' Beatrice Kunya, a nurse at Bondo District Hospital, told PLUS News recently. 'Some tell you they have not eaten for some time. Those who struggle to buy the drugs might be spending the last coin; it means they have the drug but will walk back home on an empty stomach. In fact, many of these patients decide not to come to the hospital because they know even if the disease is diagnosed, they will not afford the drug, or at times, they are unable to afford even the fees for diagnosis.'<sup>[2]</sup>

1 ITPC. Missing the Target 8. Rationing Funds, Risking Lives: World backtracks on HIV treatment, April 2010  
[http://www.itpcglobal.org/images/stories/doc/ITPC\\_MTT8\\_FINAL.pdf](http://www.itpcglobal.org/images/stories/doc/ITPC_MTT8_FINAL.pdf)

2 PLUSNews KENYA: Buckling under the financial strain of living with HIV. May 17, 2010. Available at: <http://www.plusnews.org/report.aspx?ReportID=89155>

## Addressing human rights issues in national responses to HIV

The UNAIDS Secretariat promotes seven key programmes to reduce stigma and discrimination and increase access to justice.<sup>[1]</sup> These programmes should be integral to every national AIDS response. These are programmes to:

- provide legal literacy or 'know your rights and laws';
- train health-care workers in non-discrimination, informed consent, confidentiality, duty to treat and universal precautions;
- train police in non-discrimination and in providing space for HIV outreach interventions;
- provide legal services;
- reduce stigma and discrimination;
- reform laws; and
- achieve gender equality, transform harmful gender norms and eliminate violence against women.

All these, in varying ways, protect and empower people living with HIV enabling them to be full citizens with equal rights and dignity and access to justice as well as health services.

1 Addressing human rights issues in national responses to HIV: A review of programmes to reduce stigma and discrimination and increase access to justice. Alliance, UNAIDS, 2008-2009.

### Positive Health, Dignity and Prevention in practice:

#### Advancing the Sexual and Reproductive Health and Rights of people living with HIV: A Guidance Package<sup>[1]</sup>

Developed by EngenderHealth, GNP+, ICW, the International Planned Parenthood Federation (IPPF), UNAIDS, and Young Positives, and supported by UNFPA and WHO, this guidance package raises awareness of sexual and reproductive health and rights of people living with HIV and provides 12 practical programmatic recommendations to help policymakers, programme managers, health professionals, donors, and advocates better understand specific issues that support the sexual and reproductive health and rights of different key population groups.

1 Available at: [www.gnpplus.net/programmes/sexual-and-reproductive-health-and-human-rights/policy-guidance](http://www.gnpplus.net/programmes/sexual-and-reproductive-health-and-human-rights/policy-guidance)

Priority areas to consider include the following.

- Providing a wide range of clear, up-to-date, evidence-informed options for health and well-being, in order to allow the individual living with HIV to make informed choices.
- Involving people living with HIV in all aspects of prevention, treatment, and care programmes, including of their design, programming, implementation, research, monitoring, and evaluation.
- Empowering people living with HIV to demand a comprehensive package of services to reduce their risk of TB, hepatitis, and opportunistic infections.
- Broadening HIV prevention programmes beyond focusing on the 'uninfected' and/or 'untested' and creating more discerning messages for all: HIV-negative, -positive, or -unaware.
- Focusing on the specific needs of serodiscordant couples, including discussions around safe conception, and shared responsibility within couples (e.g. partner disclosure, if, why, when, and how?)
- Further clarifying which prevention messages are relevant if both partners are HIV-positive (e.g. is it correct to focus on the continued use of condoms, based on limited data regarding the risk of re-infection and acquired resistance to antiretroviral therapy?).
- Focusing on the specific needs of key populations.
- Incorporating and understanding the connections between an individual's capacity and the effects of the wider environment.
- Providing skills-building programmes to address issues of confidence and assertiveness.
- Incorporating all aspects of sexual and reproductive health, including feelings and desires, into behavioural programming, by acknowledging the complexities surrounding the moment of transmission/acquisition of HIV.
- Integrating reproductive rights and family planning counselling and services, including regarding infertility and safer pregnancy, into the routine health services offered to people living with HIV and their partner(s) in both community and clinical settings.

Challenges include the following.

- Creating a common understanding and buy-in of Positive Health, Dignity and Prevention across all stakeholders, including policymakers, funders, and donors.
- Agreeing on the changing concept of Positive Health, Dignity and Prevention in the context of increasing access to and effectiveness of antiretroviral therapy.
- Overcoming clinical constructions of people living with HIV as objects of interventions during chronic care<sup>[12]</sup> rather than human beings with emotional, physical, mental, and sexual dimensions.
- Ensuring that health-care workers respect and understand the holistic health and prevention needs of people living with HIV.
- Integrating proven harm-reduction methods into treatment, care, and support programmes, identifying how best to respond to the individual's needs.
- Improving punitive legal and policy environments (e.g. criminalizing behaviours or status, the overly-broad criminalisation of transmission).
- Providing legal services for those subject to prosecution as well as educating judges, prosecutors, police and parliamentarians in the appropriate use of the law in the context of HIV.
- Understanding how to approach HIV-positive individuals who choose not to use condoms and/or have multiple concurrent partners.
- Assigning and agreeing on messages of shared responsibility for HIV prevention.
- Measuring the impact of the success of Positive Health, Dignity and Prevention on population health.

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12 See WHO. Chronic HIV care with ART and Prevention: Integrated Management of Adolescent and Adult Illness, Integrated Management of Childhood Illness interim guidelines for health workers at health centre or district hospital outpatient clinic, Geneva, 2007.



**V.C.T.**



# Hot topics: Three challenges and opportunities

Implementing the Positive Health, Dignity and Prevention Framework presents multiple challenges. This section briefly explores three currently topical areas highlighting some of these challenges. It suggests that viewing them through the lens of a Positive Health, Dignity and Prevention approach can provide opportunities for a radical rethink and a fresh approach.

- Stalling on universal access
- State-supported stigma and discrimination
- Treatment as prevention

## STALLING ON UNIVERSAL ACCESS<sup>[13]</sup>

*UNAIDS is committed to stand by people living with and affected by HIV and promotes the concept of Positive Health, Dignity and Prevention. With an approach that is informed by evidence and grounded in human rights, we must all support countries to achieve their universal access goals towards HIV prevention, treatment, care, and support.*

*Michel Sidibé, Executive Director, UNAIDS*

Millions of lives depend on the continued scale-up of HIV prevention, treatment, care, and support programmes. The emphasis and attempt to attain universal access goals have also benefited countries' health systems; increased the number and quality of health-care workers; improved access to health care for marginalised and vulnerable

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<sup>13</sup> Achieve, by 2010, universal access to treatment for HIV/AIDS for all those who need it is Target 6b of the UN Millennium Development Goals.

groups; and led to advances in the prevention and treatment of TB and other infections. Such goals were possible due to strong political and donor leadership that engaged and involved civil society, including organizations and networks of people living with HIV.

Despite unprecedented progress over the past decade in the move towards universal access, the most recent global data from UNAIDS suggest that for every one person starting treatment, two are newly infected<sup>[14]</sup>. Fewer than one person in five at risk of acquiring HIV has access to basic HIV prevention services<sup>[15]</sup>.

The progress also appears to be slowing down or even reversing. In its recent report, Missing the Target 8<sup>[16]</sup>, ITPC notes, 'funding from major donors such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) is stalling or flatlining...It will not be possible to build sustainable, credible health systems as the waiting lines for AIDS drugs grow.'

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<sup>14</sup> UNAIDS, Report on the Global AIDS Epidemic 2010, Geneva, 2010.

<sup>15</sup> WHO. Universal access by 2010. WHO website, Accessed April 14, 2010.

<sup>16</sup> ITPC. Missing the Target #8: Rationing Funds, Risking Lives: World backtracks on HIV treatment, April 2010.



### Challenges in implementing Positive Health, Dignity and Prevention programmes in the MENA region

The first challenge is the shortage of HIV treatment in Lebanon and most of the countries in the [Middle East and North Africa] MENA region. There are drug stockouts. For example, in 2009, in Beirut, some medication, such as Stocrin (efavirenz) was not available for seven months. Think Positive held concerts and an exhibition to fundraise for medication for people living with HIV, but it's not sufficient. The other challenge is CD4 and viral load tests, which are not covered by the Ministry of Health and cost around US\$300 every three months for the newly diagnosed and every six months thereafter. Think Positive collaborates with an international network of medical students, which provides CD4 count tests for free. In other countries in the region, such as Egypt and Jordan, there is no second-line treatment available.

Think Positive, a nongovernmental organization for and by people living with HIV, Lebanon

Recent reports from the Russian Federation<sup>[17]</sup> and Uganda<sup>[18]</sup> as well as testimony from some organizations and networks of people living with HIV involved in this Framework consultation (see sidebar on the Middle East and North Africa region), also suggest that governments are beginning to cap the number of HIV-positive people enrolled in treatment programmes and that drug stockouts are becoming increasingly more frequent.

To reverse this trend, donors must become aware that many of the values, principles, and components of Positive Health, Dignity and Prevention go hand-in-hand with the goals of achieving universal access and vice versa. Decreasing funding, capping treatment and care programmes, and allowing drug stockouts are destructive to a broad, rational response to HIV, including preventing new HIV infections.<sup>[19]</sup>

The Positive Health, Dignity and Prevention Framework fills the gap for people living with HIV not yet eligible for antiretroviral therapy but who still require care and support after receiving a positive result. This may create demand for services by motivating more undiagnosed people living with HIV to undergo earlier testing; achieve greater access for HIV-positive people to supportive services; and give people living with HIV a more compelling reason to remain in contact with their clinic between testing HIV-positive and being eligible for antiretroviral therapy.

This demand creation is an opportunity for the decentralization of health services to communities. By coordinating combination responses, creating linkages among disparate programmes and sectors, the Positive Health, Dignity and Prevention Framework will help the health sector to be more meaningfully engaged with civil society, nongovernmental organizations, and community-based organizations that are led by, and involve, people living with HIV and which already provide services that

17 Parfitt T. Russia's drug-supply system leaves HIV patients wanting. *The Lancet*, Volume 377, Issue 9763, Pages 369 - 370, 29 January 2011.

18 Geng EH, Bwana MB, Kabakyenga J, Muyindike W, Emeryonu NI, et al. Diminishing Availability of Publicly Funded Slots for Antiretroviral Initiation among HIV-Infected ART-Eligible Patients in Uganda. *PLoS ONE* 5(11): e14098. doi:10.1371/journal.pone.0014098, 2010. McNeil DG. At Front Lines, AIDS War Is Falling Apart. *New York Times*, May 9 2010. <http://www.nytimes.com/2010/05/10/world/africa/10aids.html>

19 Katabira E. Benefits of Using Antiretroviral Treatment as an Effective Prevention Tool Must Not Be Overlooked. *International AIDS Society*, January 17, 2011.

support people living with HIV to live well. These are both a cost-effective solution to scale up delivery of prevention, treatment, care, and support services and a way to support the dignity of people living with HIV who can be both providers as well as receivers of such services (e.g. clinical outreach, testing, peer support, and health education).

### STATE-SUPPORTED STIGMA AND DISCRIMINATION

*Never in the history of the international response to HIV has hope been so high in terms of treatment and medical success. And yet, that hope and that progress are threatened by increasing human rights violations, in particular HIV transmission criminalisation. We—people living with HIV organizations and networks involved in the response and our partners—must definitively try our utmost to help policymakers understand that they are on the wrong track and that an effective response must inevitably integrate respect of individuals and their basic rights.*

*Nicolas Ritter, Director, PILS (Prévention Information et Lutte contre le Sida), Mauritius<sup>[20]</sup>*

HIV-related stigma devalues people living with HIV. Self stigma is felt by people with HIV when they internalise the negative attitudes commonly associated with the virus. When HIV-related stigma (an attitude) turns into discrimination (an act) it becomes a human rights violation. Discrimination is the unfair and unjust treatment of an individual based on his/her real or perceived HIV status. Stigma and discrimination and the fear of them affect how people at risk of HIV infection consider their own risks and willingness to test for the virus.<sup>[21]</sup>

Although HIV-related stigma and discrimination exist at all levels of society, they are often reinforced by governments when codified by law: 'Laws that reinforce HIV-related stigma and prejudice impede both HIV prevention efforts and access to treatment. They do so by making populations at particular risk of infection (including injecting drug users, men who have sex with men, migrants, and sex workers) harder to reach and by sustaining the social and economic exclusion of people

20 GNP+/UNAIDS/Sidaction. Santé Positive, Dignité et Prévention: Rapport de Consultation (Positive Health, Dignity and Prevention Consultation Report) Casablanca, Morocco March 28, 2010.

21 UNAIDS. HIV-Related Stigma, Discrimination and Human Rights Violations. Geneva, 2005.

living with HIV.<sup>[22]</sup>

Governments support and enable continued HIV-related stigma and discrimination with the enactment of overly-broad HIV-specific laws that criminalize non-disclosure of HIV-positive status, potential HIV exposure, and/or non-intentional transmission of the virus. In other settings, governments ignore actions taken by the criminal justice system that allow for non-HIV-specific laws to prosecute individuals for non-disclosure of HIV-positive status, potential HIV exposure, and/or non-intentional transmission of the virus.<sup>[23]</sup>

UNAIDS<sup>[24]</sup> and advocates from civil society<sup>[25] [26] [27]</sup> argue that the use of such laws, and prosecutions using existing laws, does far more harm than good, damaging public health and ignoring international human rights conventions; and can result in the further stigmatisation and marginalisation of people living with HIV by overstating risks, creating a false sense that HIV is someone else's problem, providing further incentive for people to avoid learning their HIV status, and discouraging HIV-positive people from accessing HIV prevention resources.<sup>[28]</sup> They also argue that the significant human and financial resources devoted to a limited number of individual cases within the criminal justice system could be more productively used to expand evidence-informed and human rights-based HIV prevention efforts.

In addition, stigma and discrimination are often behind the continued criminalisation of behaviour that places people at risk of HIV—such as sex between men, sex work, and drug use. Such individuals living with HIV who engage in these often socially stigmatised behaviours are doubly stigmatised by both their HIV status and their behaviour. State-sponsored and discrimination in the form of punitive laws outlawing these behaviours often drive those subject

22 Wait, M. Law should not reinforce HIV stigma. Guardian, Friday 2 July 2010.

23 GNP+. Global Criminalisation Scan. <http://www.gnpplus.net/criminalisation/>

24 UNAIDS/UNDP. Policy Brief: Criminalisation of HIV Transmission. Geneva, 2008.

25 Jürgens, R., et al. Ten Reasons to Oppose the Criminalisation of HIV Exposure or Transmission. Open Society Institute 2008.

26 Burrell S, Cameron E, Clayton M. The criminalisation of HIV: time for an unambiguous rejection of the use of criminal law to regulate the sexual behavior of those with and at risk of HIV. Social Science Research Network, 2008.

27 Athena Network. 10 Reasons Why Criminalisation of HIV Exposure or Transmission Harms Women, 2009.

28 Bernard, E.J. HIV and the Criminal Law. NAM, 2010.



### Challenges in implementing Positive Health, Dignity and Prevention programmes in the Asia Pacific region

Participants identified unsupportive legal environments and the criminalisation of sex work, homosexuality, and drug use as issues that affect all key populations and that challenge the implementation of Positive Health programmes. Additionally, cultural and religious beliefs and practices can influence policy, which then creates challenges for implementing comprehensive programmes. Other challenges include insurance policy exclusions, the non-standardization of guidelines and policies, and a lack of policies that address Positive Health holistically—in other words policies that focus on the transmission of the virus rather than the health and well-being of the person living with HIV.

APN+ Consultation on Positive Health, Dignity and Prevention.<sup>[1]</sup>

1 Asia Pacific Network of People Living with HIV (APN+) Positive Health (Positive Health, Dignity and Prevention): Moving the agenda forward in the Asia Pacific Region. Satellite meeting at the 9th International Congress on AIDS in Asia and the Pacific, Bali, Indonesia, August 2009. (December 2009)

to these laws underground, limiting their ability to access HIV information, prevention, treatment, care and support.<sup>[29]</sup> Thus, such laws significantly hamper HIV responses; create further stigma and discrimination; and increase vulnerability to HIV and/or other illness.

Such laws and policies not only violate the human right to health,<sup>[30]</sup> they also directly contradict the values and principles of Positive Health, Dignity and Prevention. Rather, the focus must be on supportive and protective laws and policies. The Positive Health, Dignity and Prevention Framework provides the opportunity to reframe such punitive laws and policies by highlighting the damage done by these laws to HIV prevention efforts, as well as to the dignity and health of people living with HIV.

The Positive Health, Dignity and Prevention Framework requires a concerted multisectoral effort to work towards removing punitive laws and passing more laws that support and enable policies in favour of expanding programmes proven to reduce new HIV infections while protecting the human rights of people living with HIV and those who are at higher risk of exposure to the virus.

Such efforts include working towards:

- removing all HIV-specific criminal laws and limiting prosecutions under non-HIV-specific laws to intentional HIV transmission;
- removing criminal offences against men who have sex with men;
- removing criminal sanctions on sex between consenting adults, including in the context of sex work;
- allowing the provision of evidence-informed, harm reduction programmes for people who use drugs;
- enacting privacy and anti-discrimination laws that protect people living with HIV; and
- enacting laws that ensure education, prevention, and treatment programmes reach all people living with HIV, including children and adolescents born with HIV.

29 UNDP, on behalf of UNAIDS, has convened the Global Commission on HIV and the Law to examine this in great detail. The Commission will deliver its report on December 2011. See: <http://www.hivlawcommission.org/>

30 UN. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover. April 27, 2010.

## TREATMENT AS PREVENTION

A new HIV prevention paradigm emerged from the XVII International AIDS Conference 2008 in Mexico City that significantly blurred the lines between prevention and treatment—and that will have a great impact on Positive Health, Dignity and Prevention. The first was the concept of 'combination prevention': An HIV prevention approach based solely on one element does not work and can hinder the AIDS response. There is no single magic bullet for HIV prevention. Countries need to use a mix of behavioural, biomedical, and structural HIV prevention actions and tactics to suit their actual epidemic and the needs of those most at risk, just as the right combination and proportions of drugs for antiretroviral treatment is now saving millions of lives. Condoms are an essential part of combination prevention, which includes, among other elements, access to information about HIV, access to treatment, harm reduction measures, waiting longer to become sexually active, being faithful, reducing multiple partners and concurrent relationships, male circumcision, ensuring human rights, and the reduction of stigma.<sup>[31]</sup>

The second was the increasing recognition of the potential of antiretroviral therapy to greatly reduce HIV transmission risk on both an individual<sup>[32]</sup> and population<sup>[33]</sup> levels.

Treatment may be one of the single most effective prevention methods currently available. A number of studies have shown that where antiretroviral therapy is widely available and reliably accessible, it has the potential to greatly reduce HIV transmission risk between couples of different HIV status<sup>[34]</sup><sup>[35]</sup><sup>[36]</sup> and also have an impact on

new infections at a population level.<sup>[37]</sup><sup>[38]</sup><sup>[39]</sup> These results have been found in both high- and low-income countries. Consequently, there has been increasing interest in creating policies and programmes based upon a growing body of evidence demonstrating that investments in scaling up provision of antiretroviral therapy for the health of people living with HIV has an added prevention benefit.<sup>[40]</sup>

Treatment must be seen as an investment in prevention.<sup>[41]</sup> The increased return on investment and reduced long-term demand on health services that should result from the reduced rate of new HIV infections where treatment is widely available has important implications regarding universal access to treatment, through reducing the long-term cost of treatment rollout and scale-up.

It is critical, however, that the excitement over the potential public health benefits of treatment on preventing new HIV infections is tempered by an understanding that these benefits can only be realised where human rights are respected and if programmes are implemented in ways that respect and support the values and principles of Positive Health, Dignity and Prevention.<sup>[42]</sup><sup>[43]</sup>

High rates of treatment uptake cannot be achieved in an environment of stigma and marginalisation, nor where programmes are beset by potential human rights violations—such as forced or uninformed testing or coerced initiation of antiretroviral therapy primarily for the benefit public health rather than of the individual.

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31 Press Release. UNAIDS promotes combination HIV prevention towards universal access goals. Geneva, 18 March 2009.

32 See Bernard, E.J. Swiss statement that 'undetectable equals uninfected' creates more controversy in Mexico City. NAM, August 2008. Available at : [www.aidsmap.com/en/news/CB3AEAB0-8910-4B75-A6B1-3AE8B1413D2A.asp](http://www.aidsmap.com/en/news/CB3AEAB0-8910-4B75-A6B1-3AE8B1413D2A.asp)

33 See Alcorn, K. Treatment as prevention tool: enough evidence to say it works, says IAS president. NAM, August 2008. Available at: [www.aidsmap.com/en/news/30D49BD7-41FC-4E0D-AEBD-A210794D0533.asp](http://www.aidsmap.com/en/news/30D49BD7-41FC-4E0D-AEBD-A210794D0533.asp)

34 Vernazza, P., et al. « 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 (5), 2008. [English translation. (including translator's affidavit) HIV-positive individuals not suffering from any other STD and adhering to an effective antiretroviral treatment do not transmit HIV sexually. ]

35 Attia, S., et al. "Sexual transmission of HIV according to viral load and antiretroviral therapy: systematic review and meta-analysis." AIDS 23 (online edition), 2009.

36 Donnell, D., et al. "Heterosexual HIV-1 transmission after initiation of antiretroviral therapy: a prospective cohort analysis." Lancet 375 (9731): 2092–2098, 2010.

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37 Fang, C., et al. "Decreased HIV transmission after a policy of providing free access to highly active antiretroviral therapy in Taiwan." J Infect Dis 190(1): 879–885, 2004.

38 Montaner, J., et al. Association of expanded HAART coverage with a decrease in new HIV diagnoses, particularly among injection drug users in British Columbia, Canada. 17th Conference on Retroviruses and Opportunistic Infections, San Francisco, abstract 88LB, 2010.

39 Das-Douglas, M., et al. Decreases in Community Viral Load Are Associated with a Reduction in New HIV Diagnoses in San Francisco. Seventeenth Conference on Retroviruses and Opportunistic Infections, San Francisco, abstract 33, Feb 2010.

40 UNAIDS. Treatment 2.0 - Is this the future of treatment? UNAIDS Outlook, July 2010.

41 See UNAIDS. Treatment 2.0 - Is this the future of treatment? UNAIDS Outlook, July 2010.

42 Press Release. Statement on ART as Prevention: Scaling down HIV requires scaling up human rights, testing and treatment, ICASO, October 2009.

43 Strub S. Medical Ethics and the Rights of People With HIV Under Assault. POZ blogs, April 28, 2010.



## How 'treatment as prevention' policies can violate the values and principles of Positive Health, Dignity and Prevention.

In March and April 2010, the San Francisco (USA) Department of Public Health announced new HIV prevention<sup>[1]</sup> and treatment<sup>[2]</sup> policies. The prevention goal is focused on increasing testing frequency for key populations—primarily gay men—to every six months, with most of its budget being used to scale up testing and to implement its 'prevention with positives' programme. In a radical move, no part of the HIV prevention budget is aimed at HIV-negative men. The treatment goal is to treat everyone who tests HIV positive regardless of their CD4 count, in contrast to USA-wide treatment guidelines. These policies are based on emerging data from San Francisco, which found an association between reduced HIV incidence as individuals commenced antiretroviral therapy, thereby reducing community viral load,<sup>[3]</sup> and mathematical modelling that predicts a 91%

reduction in new infections over 10 years if such a policy were implemented.<sup>[4]</sup> However, clinicians are not being frank with patients as to why they are recommending treatment, implying it is for the patient's health rather than the potential public health benefit of reducing community viral load, which some advocates consider disingenuous. 'An undetectable viral load on an individual level reduces the risk of transmission—this is supported by the data. But rolling out early treatment as a public health policy is different. An individual taking treatment primarily has to derive personal benefit, given that he/she faces an individual risk from treatment. The discussion for individual treatment and public health cannot just be lumped together.'<sup>[5]</sup> In effect, San Francisco may be conducting a 'treatment as prevention' experiment without the full informed consent of participants, in violation of the values and principles of Positive Health, Dignity and Prevention.

1 Hemmelgarn, S. HIV prevention effort shifts to 'status awareness'. Bay Area Reporter, March 25, 2010.

2 Highleyman, L. SF health officials advise early treatment for people with HIV. Bay Area Reporter, April 15, 2010.

3 Das-Douglas, M., et al. Decreases in Community Viral Load Are Associated with a Reduction in New HIV Diagnoses in San Francisco. Seventeenth Conference on Retroviruses and Opportunistic Infections, San Francisco, abstract 33, Feb 2010.

4 Charlebois, E., et al. Effect of Expanded ART Strategies on the MSM HIV Epidemic in San Francisco. Seventeenth Conference on Retroviruses and Opportunistic Infections, San Francisco, abstract 33, Feb 2010.

5 Simon Collins, quoted in Horn T. Start Wars, POZ Magazine, May 5 2010.

These violations are likely to lead to loss of follow-up, poor levels of adherence, and an increase in the prevalence and transmission of drug resistant strains of HIV—all of which will undermine the potential of treatment as prevention, as well as the rights of people living with HIV.

The Positive Health, Dignity and Prevention Framework highlights that the individual living with HIV must have the right to choose if and when to start treatment. Adherence counselling both before and after initiation of antiretroviral therapy is essential to support the individual living with HIV to make informed decisions about whether and when to initiate treatment and to adhere to a treatment programme once started. Also, uninterrupted access to antiretroviral therapy is essential once treatment commences.

The following factors are likely to help policies become compatible with the Positive Health, Dignity and Prevention Framework.

- Policies that support an enabling and non-discriminatory environment in which all people living with HIV—including members of marginalised populations such as injecting drug users, sex workers, men who have sex with men, and transgender people—are able to access health services and support on the same basis as their fellow citizens will ensure the best possible coverage of treatment on a clinically indicated needs basis, thus making the most of the prevention potential of treatment.
- HIV testing should always be voluntary, include full information regarding the medical and legal consequences of testing HIV-positive, and allow for anonymity during and after testing.
- Post-test HIV counselling should always be evidence-informed and include information on sexual, drug use and disclosure decision-making without coercion. Individuals who test HIV-positive should always have a fully informed choice if and when to commence antiretroviral treatment, which can be earlier (or later) than guidelines recommend based on clinical need.
- Where access to antiretroviral therapy is limited, individuals who require treatment based on clinical need according to local guidelines should always be prioritized over those who may receive treatment for

prevention purposes (with the exception of prevention of vertical transmission).

- When there is a strong need or desire for a couple not to use condoms, ideally both the individual living with HIV, and his/her partner, should be counselled together regarding the impact of treatment on transmission risk.
- If antiretroviral therapy is to be taken as part of a combination prevention package for prevention purposes—particularly when it is taken earlier than currently recommended for health of the individual—the person living with HIV must be fully informed of, and agree to, the potential risks and benefits of such treatment on his/her health.

# WE

## PRINCIPLES

WE ARE  
**ALL RESPONSIBLE**  
FOR HIV PREVENTION

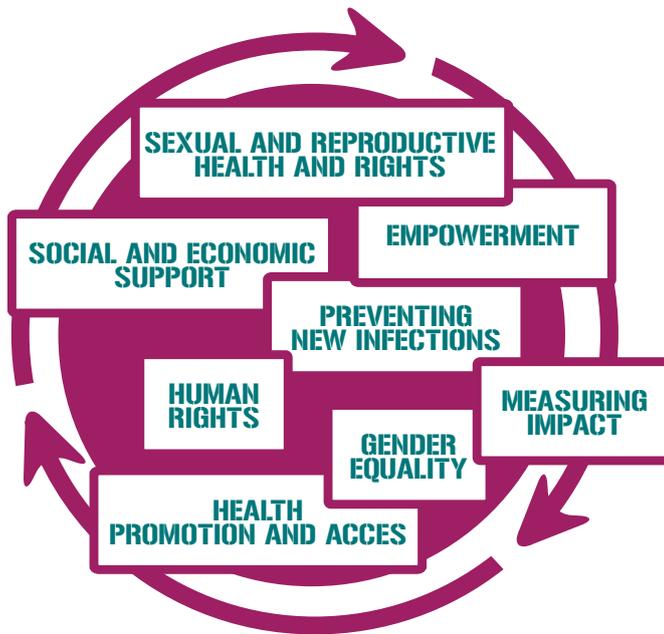
WE WILL  
**NOT BE TREATED**  
AS VECTORS OF TRANSMISSION

WE HAVE  
**NEEDS AND DESIRES**  
TO BE FULLFILLED

WE ARE MORE THAN  
**PATIENTS !**

# NEED

## PROGRAMMATIC COMPONENTS



## OUTCOME

**POSITIVE HEALTH,  
DIGNITY AND PREVENTION**

# Building evidence and measuring impact, progress and outcomes

This section highlights where evidence-building, led by people living with HIV, for many of the components of Positive Health, Dignity and Prevention is currently being gathered, analysed and disseminated, as well as ongoing current operational research into the individual elements that make up these components. It also suggests a number of indicators for monitoring and evaluation, highlighting currently available indicators and recommending further development.

## THE IMPORTANCE OF MEANINGFULLY INVOLVING PEOPLE LIVING WITH HIV

Involving people living with HIV when building evidence and measuring impact, progress, and outcomes ensures that what matters to the beneficiaries of programmes and policies informed by the Positive Health, Dignity and Prevention Framework are monitored and evaluated.<sup>[44]</sup>

Meaningfully engaging and supporting people living with HIV to develop data collection tools, conduct evaluations, and review and analyse data can result in more relevant and nuanced understandings as their uniquely lived experiences can inform these activities. This helps to ensure that programmes are continually informed by a strong and relevant evidence base that is grounded in the reality of those hoping to benefit from these programmes.

44 International HIV/AIDS Alliance. Good Practice Guide: Greater Involvement of People Living with HIV (GIPA). International HIV/AIDS Alliance/GNP+, 2010.

Strategies for harnessing individuals' life-skills and experience in building evidence and measuring impact, progress, and outcomes include:

- involving people living with HIV as participants in focus groups or surveys;
- involving people living with HIV in determining the research agenda, designing data collection tools, participating in data analysis, and contributing to conclusions and recommendations;
- training and working with peer researchers who are living with HIV;
- working with organizations and networks; of people living with HIV and
- ensuring a broad range of representation of people living with HIV who are also members of different key populations.

## BUILDING EVIDENCE

Prior to, during, and following the creation and implementation of operational guidelines, existing policies and programmes will need to be continuously evaluated for their readiness and suitability to be integrated into an evolving Positive Health, Dignity and Prevention Framework. This involves the following:

- mapping existing guidelines and policies to:
  - ↳ identify good policy and best practice in promoting the dignity and good health of people living with HIV and
  - ↳ address the lack of standardization of guidelines and policies.

- Researching and documenting impeding laws, cases of criminalisation and their impact, and violations of existing laws.
- Building partnerships and developing advocacy plans to promote holistic Positive Health, Dignity and Prevention programmes.

### Positive Health, Dignity and Prevention in practice:

#### Operational research

GNP+'s HIV prevention research programme<sup>[1]</sup> is measuring the experiences, needs, and barriers of people living with HIV in relation to the components of Positive Health, Dignity and Prevention. The research is carried out in partnership with networks of people living with HIV in Bolivia (Redbol+), Tanzania (NACOPHA), and Vietnam (VNP+) and with the Population Council and UNAIDS.

GNP+ is promoting further understanding of Positive Health, Dignity and Prevention by undertaking diagnostic studies focused on the perspectives and experiences of people living with HIV. This is an opportunity for networks of people living with HIV to explore the implications of the concept within their settings and to promote a shift in thinking on HIV prevention as it relates to people living with HIV. Using Personal Digital Assistants, people living with HIV are research coordinators, supervisors, data collectors, and interviewees, leading the process from the development of a context-specific questionnaire through to data collection, analysis of findings, report writing, and advocacy. The studies on Positive Health, Dignity and Prevention will provide networks of people living with HIV with information to evaluate countries' progress in providing a supportive and enabling environment for people living with HIV to take care of themselves, their partners, and their communities. The information gathered by people living with HIV will inform the development and implementation of national policies and programmes on HIV prevention as it relates to people living with HIV.

1 See [www.gnpplus.net/programmes/positive-health-dignity-and-prevention/operational-research](http://www.gnpplus.net/programmes/positive-health-dignity-and-prevention/operational-research)

Operational research into environmental barriers to Positive Health, Dignity and Prevention must be conducted to inform the development of appropriate programming. As part of this research, it is important to review the involvement of people living with HIV in decision-making in national HIV responses. UN and development agencies and national implementers have a role to play in promoting and supporting this research. The findings from operational research can be used to help design and improve programmes through operational guidelines, as well as advocacy tools for beneficial change.

GNP+ and its partners have produced evidence-gathering tools that meaningfully involve people living with HIV. They can also be used as monitoring tools. For example, the People Living with HIV Stigma Index provides concrete data on the stigma and discrimination experienced by people living with HIV. Implemented over time, it is possible to measure changes in their experiences.

#### THE PEOPLE LIVING WITH HIV STIGMA INDEX<sup>[45]</sup>

The People Living with HIV Stigma Index is a joint initiative of organizations that have worked together since 2004 to develop this survey, including the GNP+, ICW, IPPF, and UNAIDS.

#### THE GIPA REPORT CARD<sup>[46]</sup>

The GIPA Report Card (developed by GNP+, ICW, UNAIDS) identifies existing levels of the application of the GIPA principle in-country and provides insights on how the participation of people living with HIV can be made more meaningful.

#### GLOBAL CRIMINALISATION SCAN<sup>[47]</sup>

Since 2008, the Global Criminalisation Scan (developed by GNP+ and Regional Networks of people living with HIV) has been documenting existing legislation that criminalizes HIV non-disclosure, exposure, and transmission, as well as cases when these and non-HIV-specific laws have been used to prosecute individuals living with HIV. The aim of this in-depth research is to create a pool of knowledge that will inform advocacy plans and can be shared with other jurisdictions.

45 See [www.stigmaindex.org](http://www.stigmaindex.org)

46 See [www.gnpplus.net/programmes/empowerment/gipa-report-card](http://www.gnpplus.net/programmes/empowerment/gipa-report-card)

47 See [www.gnpplus.net/criminalisation/](http://www.gnpplus.net/criminalisation/).

### **HUMAN RIGHTS COUNT!**<sup>[48]</sup>

Human Rights Count! (developed by GNP+ and Regional Networks of people living with HIV) is a new evidence-gathering tool that aims to document cases of HIV-related human rights violations experienced by women, men, and excluded individuals living with HIV. The overall aim is to decrease the number of these human rights violations by using the information gathered to guide advocacy campaigns.

Further examples of good practice, including case studies, should be gathered by all stakeholders to assist in producing operational guidelines. Examples of evidence building by other people living with HIV-led organizations and civil society include the following.

### **GLOBAL DATABASE ON HIV-SPECIFIC TRAVEL AND RESIDENCE RESTRICTIONS**<sup>[49]</sup>

The Global Database on HIV-Specific Travel and Residence Restrictions provides updated information from 196 countries, on existing regulations denying entry or residency for people living with HIV, based on relevant country legislation.

The Database serves as a regularly updated source of information mapping the evolution of HIV-travel restrictions globally, a mechanism by which to monitor HIV-related travel restrictions and their impact, and a publicly available tool for advocacy, policy and international accountability initiatives, as well as to inform personal travel and migration. Wherever possible the database informs about the mechanisms used in practice, to support implementation and enforcement of HIV-related travel restrictions.

An initiative of Deutsche AIDS-Hilfe (DAH), the European AIDS Treatment Group (EATG) and the International AIDS Society (IAS), the Database builds on DAH's preliminary work on travel and entry regulations for people living with HIV and is a successor to earlier information provided on the EATG website.

48 See [www.gnpplus.net/programmes/human-rights/human-rights-count](http://www.gnpplus.net/programmes/human-rights/human-rights-count)

49 See <http://hivtravel.org/>

### **TREATMENT MONITORING AND ADVOCACY PROJECT (TMAP)**<sup>[50]</sup>

Launched in 2005 by the International Treatment Preparedness Coalition (ITPC), the TMAP identifies barriers to delivery of HIV services and holds national governments and global institutions accountable for improved efforts.

The ITPC local/regional/global structure is utilized by TMAP to initiate monitoring and advocacy to:

- hold country governments and multinational and bilateral organizations and donors accountable for progress in the scale-up of HIV treatment;
- monitor and critique challenges, accomplishments, and lessons learned in treatment delivery at the country level and make concrete recommendations for improvement to national governments, international institutions, and donors; and
- support the growing capability of civil society as evidence-based monitors and advocates.

Since inception, TMAP has produced eight reports identifying barriers to scale-up of quality programming and making concrete recommendations to governments and global agencies. The Missing the Target<sup>[51]</sup> series of reports remains unique in the world of HIV and global health, offering a comprehensive, objective, on-the-ground analysis of issues involved in delivery of HIV services that is 'owned' by civil society health consumers themselves.

In addition, TMAP supports its country teams to undertake advocacy based on the specific research/survey findings in their country to push for improved and sustained responses on the national and international level. Since 2008, TMAP has also aimed to make a sustained contribution to delivery of HIV and health services in low- and middle-income countries by providing ongoing 'south-to-south' mentoring and capacity building. In addition, TMAP's Global Fund Country Coordinating Mechanisms (CCMs) Monitoring Project is assessing whether (and how) civil society representatives are able to use their positions on CCMs to have direct impact in making Global Fund programmes more successful.

50 See [www.itpcglobal.org/index.php?option=com\\_content&task=view&id=103&Itemid=12](http://www.itpcglobal.org/index.php?option=com_content&task=view&id=103&Itemid=12).

51 See [www.itpcglobal.org/index.php?option=com\\_content&task=view&id=74&Itemid=11](http://www.itpcglobal.org/index.php?option=com_content&task=view&id=74&Itemid=11).



**Positive Health, Dignity and Prevention in practice:**

**ICASO's Prevention and Treatment Advocacy Project (PTAP)**

In 2005, the International Council of AIDS Service Organizations (ICASO) began its implementation of a global five-year community mobilisation and advocacy project in 10 countries: Belize, Botswana, China, India, Jamaica, Kenya, Nigeria, the Russian Federation, Rwanda and Ukraine. This project, the 'Community-Based Advocacy and Networking to Scale-Up HIV Prevention in an Era of Expanded Treatment,' is better known as the Prevention and Treatment Advocacy Project (PTAP). PTAP is contributing to national and state policy and programming shifts to increase access to comprehensive HIV prevention alongside expanded treatment for HIV. The project has done this by mobilizing the national community sector and creating a pool of dynamic and skilled advocates. In 2007, ICASO undertook a study to document the country-level achievements and challenges of PTAP and, in 2008, published an impact review<sup>[1]</sup> that demonstrates how PTAP's structure—based on national focal point organizations working with local community networks and supported by regional and global organizations—has built a strong mechanism for effective national community sector advocacy on AIDS. The report shows that community mobilisation and advocacy are powerful tools for bringing about policy change.

1 ICASO PTAP. Community Advocacy for Policy Change: Scaling Up Prevention Alongside Treatment. An Impact Report, 2008.

## MEASURING IMPACT, PROGRESS AND OUTCOMES

Steps should be taken to monitor and evaluate efforts to implement Positive Health, Dignity and Prevention during the entire process of moving from policy framework to operational guidelines and beyond.

### DEVELOPMENT OF MONITORING AND EVALUATION INDICATORS FOR POSITIVE HEALTH, DIGNITY AND PREVENTION IMPLEMENTATION

Monitoring and evaluation indicators specific to the objectives and goals of Positive Health, Dignity and Prevention must be designed in collaboration with the UNAIDS Monitoring and Evaluation Division (MERG). Once a draft consisting of existing and new indicators has been proposed, they should be submitted to the MERG for approval. Such indicators should cover the following areas.

- Stakeholder knowledge of Positive Health, Dignity and Prevention Framework/operational guidelines
- Policy dialogue
- Integration and services
- People living with HIV involvement and leadership
- Quality of programmes and services
- Health outcomes
- Prevention of new infections
- Human rights, stigma, and discrimination

### SHORT-TERM USE OF CURRENT INDICATORS FOR MONITORING POSITIVE HEALTH, DIGNITY AND PREVENTION POLICY AND PROGRAMMES

In the short term, it is important to draw on existing indicators and monitoring tools to reflect on the following.

- Is our work supporting people living with HIV?
- If so, what is the quality of that work? Has it been respectful? Has it been responsive?
- Has our work been in close coordination with networks or organizations of people living with HIV?
- Do our programmes reflect the priorities and issues of people living with HIV as articulated by them?

Current indicators (e.g. National Composite Policy Index [NCPI] UNGASS indicators<sup>[52]</sup>) or those used for the Stigma Index may also be helpful in assessing advocacy and policy dialogue, as well as the planning, implementation, and integration of operational guidelines.

### NCPI UNGASS INDICATORS<sup>[53]</sup>

The NCPI measures progress in the development and implementation of national HIV policies, strategies and laws. It is an integral part of the core UNGASS indicators. Part A is provided by government officials. Part B is provided by representatives from civil society organizations, bilateral agencies, and UN organizations. NCPI responses reflect the overall policy, strategy, legal, and programme implementation environment of the HIV response. The process of reviewing NCPI UNGASS indicators—from both government and civil society—can raise awareness and provide an extremely valuable space for people living with HIV to report and engage in advocacy both at the country level and internationally.

52 UNAIDS. Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on Construction of Core Indicators: 2010 Reporting.

53 Available at [http://data.unaids.org/pub/Manual/2009/JC1676\\_Core\\_Indicators\\_2009\\_en.pdf](http://data.unaids.org/pub/Manual/2009/JC1676_Core_Indicators_2009_en.pdf)



# Moving forward

The main goals of Positive Health, Dignity and Prevention are to improve the dignity, quality, and length of life of people living with HIV; which, in turn, will have a beneficial impact on partners, families, and communities, including reducing the likelihood of new infections.

Policies and programmes adapted to individual needs -that support these goals- must be scaled-up and supported, especially those that are community owned and led.

In order to move forward towards making these goals a reality, we recommend focusing on the following nine action areas.

## 1 ADVOCACY

To increase the meaningful and broad-based mobilisation of people living with HIV in HIV prevention efforts and increase the capacity of organizations and networks of people living with HIV at global, regional, and country levels to participate as full, equal, and essential partners in the planning, implementation, monitoring, and evaluation of Positive Health, Dignity and Prevention initiatives at global, regional, and country levels.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Work with key partners supporting advocacy work and develop regional and local advocacy plans.	GNP+	PLHIV networks civil society UNAIDS
Mobilize funding <sup>[1]</sup> and technical support facilities to support civil society capacity building for funding to provide further services and resources for Positive Health, Dignity and Prevention policies and programmes.	UNAIDS	GNP+ PLHIV networks civil society Donor agencies
Implement mentoring programmes, regional skills-building workshops, and focused support for key PLHIV organizations.	UNAIDS	GNP+ PLHIV networks civil society

<sup>1</sup> Ensuring that the UNAIDS Unified Budget, Results and Accountability Framework (UBRAF) <http://www.unaids.org/en/ourwork/managementandexternalrelationsbranch/financialmanagementandaccountabilitydepartment/ubraf/> includes funding for operationalising the Positive Health, Dignity and Prevention framework.

## 2 BUILDING EVIDENCE

To evaluate existing policies and programmes for their readiness to be integrated into the Positive Health, Dignity and Prevention Framework; to provide evidence of existing good practice.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Gather further evidence on the needs of PLHIV to highlight gaps in knowledge and to help understand priority areas.	GNP+	PLHIV networks civil society
Analyse existing data sources, including Stigma Index, Criminalization Scan, Human Rights Count, GIPA Report Card.	GNP+	PLHIV networks civil society
Audit current guidelines to evaluate how to address the lack of standardisation of current guidelines and policy in terms of the Positive Health, Dignity and Prevention framework.	UNAIDS	UNAIDS cosponsors

## 3 DISSEMINATION

To ensure the robust endorsement, adoption, and implementation of the Positive Health, Dignity and Prevention Framework by key stakeholders at global, regional, and country levels.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Engage PLHIV, policymakers, and programmers to support the framework and promote its implementation across settings through production of information, education, and communication materials for the framework and engaging and involving the media and community.	GNP+ UNAIDS	PLHIV networks civil society public sector private sector UNAIDS cosponsors donor agencies

## 4 POLICY DIALOGUE

To agree on priority areas for implementation, including linkages between existing programmes, and to understand gaps in current policies relating to prevention by PLHIV.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Implement broad consultation with key stakeholders.	GNP+ UNAIDS	PLHIV networks civil society public sector private sector UNAIDS cosponsors Donor agencies

## 5 PLANNING

To prepare for standard operational guidelines for Positive Health, Dignity and Prevention.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Map strategic sectors where the Framework can be applied, including health, education, financial services, community strengthening, youth movements, social movements.	GNP+ UNAIDS	PLHIV Networks Civil society Public sector Private sector UNAIDS cosponsors Donor agencies
Plan for baseline studies, operational research, and evaluation, for example, evidence gathering on the lived experiences of PLHIV regarding components of Positive Health, Dignity and Prevention and an assessment of legal environments and how they impact on HIV prevention programming.	GNP+ UNAIDS	PLHIV networks civil society
Produce best practice document describing linkages between the components of Positive Health, Dignity and Prevention on policy and programmatic levels.	GNP+ UNAIDS	

## 6 IMPLEMENTATION

To develop standard operational guidelines for Positive Health, Dignity and Prevention.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Implement broad consultative process with partners and other stakeholders.	GNP+ UNAIDS	PLHIV Networks Civil Society UNAIDS cosponsors Donor agencies

## 7 INTEGRATION

To integrate standard operational guidelines into national strategic frameworks, resources, plans, policies, and monitoring and evaluation systems.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Ensure inclusion of Positive Health, Dignity and Prevention Framework in national strategic frameworks, resources, plans, policies, and monitoring and evaluation systems.	GNP+ UNAIDS	PLHIV networks civil society public sector private sector UNAIDS cosponsors donor agencies

## 8 MONITORING AND EVALUATION

To develop monitoring and evaluation indicators for implementation of the Positive Health, Dignity and Prevention Framework, including programme linkages, policy development, and impact on new infections and individual and population health outcomes.

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Identify and adapt indicators for Positive Health, Dignity and Prevention across settings and services, drawing on the work of the MERG.	UNAIDS	GNP+ UNAIDS cosponsors
Build capacity of Monitoring and Evaluation Advisers to work with PLHIV organizations and networks on monitoring and evaluating Positive Health, Dignity and Prevention programming at the country level.	UNAIDS	PLHIV networks civil society UNAIDS cosponsors Donor agencies
Monitor government accountability regarding funding and policy commitments.	GNP+	PLHIV networks civil society

## 9 ADAPTATION AND IMPROVEMENT

To adapt framework and operational guidelines based on monitoring and evaluation and as the epidemic changes, more evidence is acquired, and other changes occur (e.g. new prevention technologies, better understanding of treatment as prevention, changes enabling or disabling funding, policy and legal environments).

ACTIVITIES	LEAD(S)	OTHER PARTNERS
Develop a best practices document based on community-based research and other evidence for further policy and programme development.	GNP+	PLHIV networks civil society
Continue dialogue amongst partners and stakeholders to understand and agree how to adapt the framework and fine-tune the operational guidelines.	GNP+ UNAIDS	PLHIV networks civil society public sector private sector UNAIDS cosponsors donor agencies



## APPENDIX 1 FRAMEWORK DEVELOPMENT BACKGROUND

Consultations with people living with HIV on HIV prevention began in Monaco in January 2008 as a prelude to a summit titled LIVING 2008, which took place before the XVII International AIDS Conference in Mexico in July-August 2008. The sessions on 'Positive Prevention' at LIVING 2008 generated much debate and controversy.

Subsequently, the Global Network of People Living with HIV (GNP+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) co-organized an International Technical Consultation in Tunisia in April 2009, where participants agreed on a new concept: Positive Health, Dignity and Prevention.

Later in June 2009, the Asia Pacific Network of People Living with HIV (APN+) held consultations on Positive Health, Dignity and Prevention in Bangkok during its Annual General Meetings.

In August 2009, a meeting convened by the Indonesian Network of People Living with HIV (JOTHI), APN+, GNP+, and UNAIDS sought to explore programmatic, policy, and research priorities within the Asia Pacific region and to agree on ways to move the issue of Positive Health (the term used in the Asia Pacific region in place of Positive Health, Dignity and Prevention) forward through the work of different stakeholders invited to the meeting.

Since then, GNP+ and UNAIDS have shared the outcomes of the meeting with a range of partners. Additionally, GNP+ and UNAIDS met with several United States Government agencies—the Centers for Disease Control and Prevention (CDC), the United States Agency for International Development (USAID), and Department of Defense (DoD)—to explore opportunities to work together to translate the Positive Health, Dignity and Prevention concept into practice.

In early 2010, GNP+ undertook consultations and operational research with the Population Council and national networks of people living with HIV in Bolivia (Redbol+), Tanzania (NACOPHA), and Viet Nam (VNP+).

A joint GNP+ and UNAIDS consultation with the international francophone community was held in Casablanca in March 2010 in collaboration with Sidaction.

Work on the Framework began in Spring 2010 and involved consultations with a wide range of stakeholders.

Regional organizations/networks of people living with HIV and civil society stakeholders consulted include the following.

- Asia Pacific Network of People Living with HIV (APN+)
- AIDS and Rights Alliance of Southern Africa
- Caribbean Regional Network of People Living with HIV/AIDS (CRN+)
- Community Health Media Trust, South Africa
- Global Network of People Living with HIV, North America (GNP+NA)
- Indian Network for People Living with HIV/AIDS (INP+)
- National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK)
- Panos, Zambia
- Treatment Action Campaign (TAC), South Africa
- Think Positive, Lebanon

Public sector stakeholders consulted included the following.

- Malawi government, Office of the President and Cabinet; Department of Nutrition and HIV/AIDS
- National Centre for AIDS Control and Prevention (CENSIDA), Mexico

UNAIDS and its cosponsors consulted included the following.

- UNAIDS Civil Society Partnerships, Human Rights, Prevention, TB and Monitoring, Operations Research and Evaluation (MOE) Teams
- UNAIDS Regional Support Team for West and Central Africa
- UNAIDS Sub-Regional Perú-Bolivia-Ecuador Office
- UNDP, UNESCO, UNFPA, UNICEF and WHO Department of HIV/AIDS

Donor agencies consulted included the following.

- CDC Global AIDS Program
- USAID—USAID | Health Policy Initiative, Task Order 1 (Headquarters and Mexico country office)
- USAID Office of HIV/AIDS
- United States Department of Defense

## APPENDIX 2 FURTHER READING

### CONSULTATION REPORTS

GNP+/UNAIDS. Technical Consultation Report: Positive Health, Dignity and Prevention. Tunis, April 2009.

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GNP+/UNAIDS/Sidaction. Santé Positive, Dignité et Prévention: Rapport de Consultation (Positive Health, Dignity and Prevention Consultation Report). Casablanca, Morocco March 28, 2010.

INP+. National Level Consultation on Positive Prevention, New Delhi, February 2010.

### USEFUL DOCUMENTS

ActionAid International/CARE USA/Global Health Council/ GNP+/Grupo Pela Vida/Hong Kong AIDS Foundation/ ICASO/International Federation of Red Cross and Red Crescent Societies/International Harm Reduction Association/International HIV/AIDS Alliance/World Council of Churches. Code of Good Practice for NGOs Responding to HIV/AIDS.

Global HIV Prevention Working Group. Behaviour change and HIV prevention: (re)considerations for the 21st century, 2008.

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The Inter-Parliamentary Union/UNDP/UNAIDS. Taking action against HIV: A handbook for parliamentarians, 2007.

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WHO. Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings. Geneva, 2008.

WHO. Monitoring and reporting on the health sector's response towards universal access to HIV/AIDS treatment, prevention, care and support 2009–2010. WHO framework for global monitoring and reporting, 2009.

WHO. Priority HIV and sexual health interventions in the health sector for men who have sex with men and transgender people in the Asia-Pacific Region, 2010.

