

Code of Good Practice for NGOs responding to HIV/AIDS

UNEDITED DRAFT FOR CONSULTATION

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Chapter 1 – Introduction

1.1 Context

HIV/AIDS is an unprecedented, global development challenge, which has already caused too much hardship, illness and death. Over 40 million people world wide are now living with HIV/AIDS, of whom 2.5 million are children and young people under the age of fifteen years.¹ HIV infection and AIDS death rates continue to rise. In 2003 5 million people were newly infected with HIV, and 3 million people dying of AIDS.²

Today, human security is being threatened by HIV/AIDS, as the virus destabilizes society and the state in various ways—as the economically active succumb to AIDS-related illnesses, families, households, workplaces, and communities are disrupted, income levels are reduced, the social fabric undermined, and economies are weakened.³

The UN Millennium Declaration and the goals it sets, highlight the interconnectedness between development goals and addressing the causes of vulnerability to HIV/AIDS and its impacts by alleviating poverty through sustainable development, promoting gender equality and access to education.⁴

Social, cultural, economic and legal factors exacerbate the spread HIV and heighten the impact of HIV/AIDS. In almost all cases, poor and socially marginalised people are disproportionately vulnerable to HIV/AIDS and its consequences. The overwhelming burden of the epidemic is in developing countries, where the vast majority of the people who are most affected by and vulnerable to HIV/AIDS do not yet have access to a basic set of quality HIV prevention, treatment, care and support services and programmes.⁵

1.2 Building on the global momentum

In recent years there has been growing global momentum to address the global HIV/AIDS crisis, greater than at any other time in the course of the pandemic. The United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001 resulted in the unanimous adoption by member states of the *Declaration of Commitment on HIV/AIDS*.⁶ The Declaration is a “water shed in the history of the epidemic [and] for the first time sets time

¹ *AIDS Epidemic Update*, Joint United Nations Programme on HIV/AIDS (UNAIDS) World Health Organization (WHO), December 2003.

² *AIDS Epidemic Update*, UNAIDS and WHO, at page 3.

³ HIV/AIDS and security, see

http://www.unaids.org/en/in+focus/hiv_aids_security+and+humanitarian+response.asp

⁴ *UN Millennium Declaration*, Resolution adopted by the General Assembly, 55th Session, 8th September 2000, A/RES/55/2. An overview of the Millennium Development Goals is available at <http://www.un.org/millenniumgoals/>

⁵ 95% of people with HIV/AIDS live in developing countries. *A commitment to action for expanding access to HIV/AIDS Treatment*, International HIV Treatment Access Coalition, December 2002. Globally fewer than one in five people at risk of infection have access to basic prevention services.

Access to HIV Prevention: Closing the Gap, Global Prevention Working Group, May 2003 at page 2.

⁶ *Declaration of Commitment on HIV/AIDS*, United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in 25 – 27 June 2001,

<http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>

bound targets to which Governments and the United Nations may be held accountable".⁷ Non Government Organizations (NGOs) are playing a critical role in advocating, at both national and international level, for governments, UN agencies, among others to take concrete action in order to achieve the identified targets and make the commitments set out in the Declaration a reality.⁸

Financial resources are being more effectively mobilised in an effort to scale up proven strategies to address HIV/AIDS. The budgeted funding for HIV/AIDS in 2003 totalled \$4.2 billion and actual spending on global HIV/AIDS in this period totalled around \$3.6 billion.⁹ While this falls short of the estimated \$10.7 billion needed by 2005, the progress in resource mobilisation is encouraging.¹⁰

The life saving benefits antiretroviral (ARVs) have been experienced predominately in industrialized countries, while millions of people in developing countries continue to die each year. Between 5 and 6 million people in developing countries urgently need access to ARV therapy.¹¹ NGOs have played a significant role in highlighting this fundamental inequity, bringing pressure to bear on governments, the UN system, and pharmaceutical companies to respond.

While there are challenges in providing HIV treatment to large numbers of people in resource limited settings, significant steps are now being taken to do so. Drug prices have also fallen in recent years, particularly in the wake of increased generic competition the pharmaceutical sector. In September 2003, the World Health Organization (WHO) declared lack of access to ARVs a global health emergency. On World AIDS Day in 2003, WHO and UNAIDS released a global initiative aiming to provide antiretroviral therapy to 3 million people with HIV/AIDS in developing countries by the end of 2005.¹²

1.3 Applying the lessons learnt

In the 20 years since AIDS was first reported, research and practice have generated an impressive body of knowledge and tools about how to reduce the transmission of HIV, provide quality treatment, care and support for people affected by HIV/AIDS and alleviate the impact of the pandemic. This Code draws on the knowledge and experience gained over the last 20 years, to support and encourage good practice. While learning will continue, we must harness the current momentum and make a concerted effort to apply what we already know in scaling up services and programmes that can make a dramatic difference to the future evolution of the HIV/AIDS pandemic. We must concentrate our resources where they will make the most difference to slow the spread of the epidemic and mitigate its impact. This requires focused support to the most affected populations, full and meaningful involvement of all people living

⁷ Report of the Secretary General on progress towards implementation of the Declaration of Commitment on HIV/AIDS, United National General Assembly, August 2002, A/57/227.

⁸ *Stories from the front lines: Experiences and lessons learned in the first two years of Advocacy around the Declaration of Commitment*, International Council of AIDS Service Organizations (ICASO), September 2003.

⁹ *Global funding for HIV/AIDS in resource poor settings*, Summers, T. and Kates, J., Kaiser Foundation, December 2003.

¹⁰ *Macroeconomics and health; Investing in health for economic development*, Commission on Macroeconomics and Health, WHO, December 2001. <http://www3.who.int/whosis/cmh>

¹¹ *A commitment to action for expanding access to HIV/AIDS Treatment*, International HIV Treatment Access Coalition, December 2002, http://www.who.int/hiv/pub/arv/who_hiv_2002_24.pdf

¹² *Treating 3 million by 2005 - Making it happen*, WHO, December 2003.

<http://www.who.int/3by5/publications/documents/isbn9241591129/en/print.html>

with HIV (PLHA), a constant fight against stigma and discrimination, a commitment to empowerment for girls and women, and respect for the diversity of human sexuality and relationships.

1.4 Fostering partnerships

No one organisation or institution can respond to HIV/AIDS in isolation, given the diversity and complexity of needs that it creates. The pandemic demands mobilisation and collaboration at community, national and international levels. Government, civil society and the private and public sectors all have vital roles to play. We need to ensure that we complement each other's strategies and actively collaborate, while respecting each other's independence and acknowledging differences. Transparency, critical thinking, learning and sharing are essential elements of successful partnerships.

1.5 Strengthening the unique role of NGOs

NGOs and Community Based Organizations (CBOs) have been at the forefront of the HIV/AIDS response since the beginning of the pandemic, often taking a leading role in advocating for marginalized and vulnerable communities and facilitating their active participation in the HIV/AIDS response. The most successful responses to HIV/AIDS and other development challenges are built upon local leadership, commitment and responsibility, and supported by knowledge, learning and resources.

What do we mean by NGO?

For convenience we use the term NGO to encompass the wide range of organizations that can be broadly characterised as 'not for profit' and 'non – government' including CBOs, Faith Based Organizations (FBOs), and organizations of affected communities including people living with HIV/AIDS, sex workers, women's groups, among many others, who are active in the HIV/AIDS response. See also section 1.6 below that sets out the target audience for the Code.

What do we mean by 'affected communities'?

The term is used to encompass the range of people affected by HIV/AIDS including carers, partners and family members of PLHA, orphans and children affected by HIV/AIDS and people at particular risk of HIV infection. Depending on the nature of particular epidemics, this may include women and girls, young people, sex workers and their clients, people who inject drugs (IDU), men who have sex with men (MSM), mobile and incarcerated populations.

In order to be effective, NGOs must have credibility with the communities with whom they work. A genuine commitment to the involvement of PLHA and affected communities in responding to HIV/AIDS is not simply the expression of an ethical commitment to empower communities to take control and improve their own health. Rather, it acknowledges that the experience of individuals and communities is an essential ingredient to effective community responses to the challenges of HIV/AIDS. It is at the level of individuals and communities that the impacts of HIV/AIDS are felt and HIV infection occurs. Communities themselves must take up the challenges posed by HIV and work to find solutions that are appropriate for them. When efforts to respond to HIV/AIDS are grounded in the lived experiences of those affected, they are far more likely to address the social factors that shape HIV risk, HIV transmission, and the experience of living with HIV/AIDS.

An important and unique role of NGOs is to take an active role in advocating for the accountability of governments, private sector, UN agencies among others, in the HIV/AIDS response. It follows then that NGOs too are accountable to the community they represent and serve. Accountability, transparency and effective stewardship of resources are crucial to

developing and maintaining credibility both with communities, as well as governments and private donors that provide the necessary resources. This imperative is highlighted as scaling up the HIV/AIDS response gathers greater momentum. NGOs are benefiting from increased availability of resources. However, there is some concern that NGOs are becoming more accountable to donors than to their declared constituencies.¹³ This underscores the need for rigour in and commitment to accountability.¹⁴ Accountability to and a demonstrated involvement of communities strengthens the legitimacy of the NGO advocacy voice in the HIV/AIDS response. NGOs must protect and maintain the right to independently determine their own priorities, including their unique advocacy role, in line with the needs and aspirations of their communities.

1.6 About the Code

What the Code is for

The Code of Practice provides guidance to the work of Supporting NGOs (see *Who is the Code for* below) and can be utilized in variety of different ways. NGOs may find the principles outlined in this Code of value in guiding their own work, as well as a useful statement of Supporting NGOs accountability that can strengthen the relationship between Supporting NGO and their NGO partners.

The principles set out in this Code can be used to guide:

- organizational planning
- the development, implementation and evaluation of programmes, including advocacy programmes designed to create and sustain a supportive legislative and policy environment for effective programming and that promote the rights of people living with HIV/AIDS and affected communities
- advocacy efforts to ensure effective scaling up of HIV/AIDS programmes and
- allocation of resources based the principles the Code outlines.

Who is the Code for

It is envisaged that this Code can be used to support the work of NGOs undertaking HIV/AIDS work generally. However, given the diversity and complexity of the global pandemic and the wide variety of NGOs engaged in HIV/AIDS, this Code is focused on promoting good practice among NGOs that provide technical, and/or financial and/or capacity development, advocacy. We refer to this target audience for the Code as 'Supporting NGOs'. The project is focussing on encouraging Supporting NGOs to become signatories to the Code. This approach does not preclude NGOs working in particular countries from becoming signatories to the Code if they wish. (Also see Future of the Code).

Supporting NGOs that 'sign on' to the Code agree to be held accountable to the principles outlined in the Code and promote the utilization of the Code in their work with their NGO partners. Supporting NGOs may be international, regional and in country NGOs. Supporting NGOs may play different roles, some of these include:

- provision of HIV/AIDS services, programmes and advocacy initiatives in country

¹³ *A Question of Scale? The Challenge of Expanding the impact of Non-Governmental Organizations' HIV/AIDS Efforts in Developing Countries*, DeJong, J. Horizons and International HIV/AIDS Alliance, August 2001. See section 4.5 Scaling up.

¹⁴ In the context of this Code Supporting NGOs consistencies include their NGO partners, including CBOs, FBOs, organizations of affected communities including people living with HIV/AIDS, sex workers, women's groups, among many others.

- provision of broader health, development, humanitarian assistance through services, programmes and advocacy initiatives that incorporate HIV/AIDS related work
- technical assistance, financial support, capacity development and advocacy in partnership with NGOs in country and
- financial support and operational assistance in establishing NGOs in country and provisions of technical assistance and capacity development to ensure sustainability.

It is not intended that signatory Supporting NGOs commit to delivery of the full range of activities outlined in the Code. Often Supporting NGOs assist other NGO to provide a range of programmes outlined in Chapter 4, so the Code includes good practice principles for programming, although Supporting NGOs may not provide these programmes directly. Some Supporting NGOs may also specialize in supporting NGOs to deliver specific types of services and programmes such as providing home care services or HIV prevention programmes. It is critical that signatory NGO commit not to undermine the work of other NGOs. For example, where a Supporting NGOs provides care and support programmes, that they do not undermine the work of NGOs providing prevention programmes. The comprehensive range of programmes outlined in Chapter 4 can also be used to guide advocacy efforts to ensure that the essential package of programmes and services are available where they are needed.

Project purpose

Through the development of this Code of Good Practice for NGOs involved in HIV/AIDS response this project aims to:

- outline, and build wider commitment to, the principles, practices and evidence base that underscores successful NGO HIV/AIDS work
- assist Supporting NGOs to improve the quality and cohesiveness of their work and their accountability to their NGO partners and beneficiary communities
- foster greater collaboration between the wide variety of Supporting NGOs now actively engaged in responding to the HIV/AIDS pandemic and
- reinvigorate the 'voice' of NGOs in the HIV/AIDS response by committing to a shared advocacy agenda.

How the Code came about

In last ten years there has been a considerable increase in the number and range of NGOs specialising in HIV/AIDS work. There has also been an increasing number of humanitarian and development NGOs taking on, or expanding their role in, HIV/AIDS work, as the impact of the pandemic deepens. This is likely to continue given the commitments set out in the *Declaration of Commitment on HIV/AIDS, 2001* and the corresponding need to rapidly enlarge the scale of HIV/AIDS activities. This is presenting new challenges, particularly in ensuring that the lessons learnt over the last 20 years are used to guide the allocation of resources and the scaling up of HIV/AIDS programmes.

The proliferation of HIV/AIDS NGOs has, at times, occurred at the expense of accountability and quality programming. NGOs are often under resourced, and lack the technical skills or experience in applying the most effective methods for good programming, monitoring and evaluating their activities and supporting organizational development. There is also a sense that the changing nature of NGO involvement in HIV/AIDS and changes in the global funding environment, have led to fragmentation of the NGO 'voice' in the HIV/AIDS response.

With these challenges in mind NGOs from around the world convened a Civil Society Consultation meeting in November 2002. A strong consensus emerged about the need to harness the growing global commitment to HIV/AIDS by supporting and strengthening the role

of NGOs in the HIV/AIDS response. Initiatives such as the *Code of Conduct for the International Red Cross and Red Crescent Movement and NGOs in Disaster Relief* and the Sphere Project's *Humanitarian Charter and Minimum Standards in Disaster Relief* were considered valuable models for how this could be achieved.

Drawing on the experiences of this work, NGO present at this meeting agreed to develop a voluntary Code of Practice for NGOs involved in HIV/AIDS response. A steering committee of NGOs interested in supporting the initiative was formed. Participating NGOs have provided human and financial resources to undertake the work involved.¹⁵

Structure of the Code

Design note: diagram to be included that illustrates text below (text to be deleted).

This Code is divided into 5 chapters. Chapter one is introductory. Chapter two sets out the guiding principles that provide the overarching framework for the more specific Good Practices Principles set out in Chapters 3 and 4. The guiding principles outline NGO signatories commitment to a set of human rights and public health principles. These principles are then applied to the kinds of work that NGOs do and how they do it, in the more specific good practice principles set out in Chapters 3 and 4.

Chapter 3 focussed on the operational aspects of running an NGO and includes good practice principles in governance, management, programme planning and involvement of PLHA and affected communities and access and equity in programming. Chapter 4 provides good practice principles in key areas of NGO activity; prevention, treatment, care and support, addressing stigma and discrimination, impact mitigation, and scaling up HIV/AIDS programmes. Within each of these areas of activity, consideration is given not only to Good practice principles in relation to services and programmes, but also in relation to advocacy initiatives. Key resources and references provide the evidence which supports the principles, as well as resources that can assist putting these principles in to practice.

Implementation of the Code and future of the Project

In the coming months the Committee will consider how the Code can be implemented and how we might build upon on the work in future. The consultation process will involve gathering NGOs views on implementation of the Code and future of the project to inform the Committee's decisions. The International Federation of Red Cross and Red Crescent Societies' website will be updated prior to the Bangkok International AIDS Conference, to provide more detailed information about strategies for implementation of the Code and what 'signing on' to the Code will involve. The Project Steering Committee envisages that the final version of the Code will be launched on World AIDS Day 2004.

¹⁵ See Chapter 5 – Section 5.2.

Chapter 2 – Guiding Principles

2.1 Core values

The motivation for and commitment to responding to HIV/AIDS is underscored by core values that guide both what we do and how we work.

At the centre of our work is our commitment to:

- valuing human life
- respecting the dignity of all people
- respecting diversity and promoting the equality of all people without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion
- preventing and eliminating human suffering,
- supporting community values that encourage respect for others and a willingness to work together to find solutions, in the spirit of compassion and mutual support
- addressing social and economic inequities and fostering social justice.

These values are common values - that underpin HIV/AIDS NGOs and humanitarian and development NGOs.¹⁶ While the language of human rights may seem distant from the day to day struggles we face in our work, many of these same values also find expression in the *Universal Declaration of Human Rights*.¹⁷

2.2 Integrating human rights and public health approaches to HIV/AIDS

The challenges presented by the HIV/AIDS pandemic have brought in to stark relief the need for public health strategies to protect human rights as an integral part of an effective response.

The goal of promoting and protecting the well being of all people is common to both human rights and public health action. Central to this task is identifying and responding to those particularly vulnerable to ill health. There are also differences which need to be acknowledged. Human rights action focuses on the protection and promotion of rights, freedoms and dignity of individuals.¹⁸ Public health action seeks to influence the social factors that impact on health, and as such focuses on the health needs of the population as a whole.

Given these different perspectives, public health strategies seeking to promote population health outcomes can be in direct conflict or indirectly undermine the promotion and protection of individual human rights.¹⁹ However, the experience of responding to HIV/AIDS has forged a greater understanding about how and why the protection of human rights supports effective public health outcomes. Compulsory testing of sex workers, for example, violates the human

¹⁶ See for example, International Federation of Red Cross and Red Crescent Societies outline of humanitarian values at <http://www.ifrc.org/WHAT/values/hvalues/>

¹⁷ *The Universal Declaration of Human Rights*. <http://www.unhcr.ch/udhr/lang/eng.htm>

¹⁸ 'Human rights' refer to internationally agreed principles and norms enshrined in international human rights law, and encompass civil, political, cultural, economic and social rights.

¹⁹ A useful framework for negotiating the balance between public health and human rights when the goals may appear to conflict is set out in *AIDS, Health and Human Rights – An explanatory Manual*, International Federation of Red Cross and Red Crescent Societies and Francois-Xavier Bagnoud Center for Health and Human Rights Harvard School of Public Health, 1995, at pages 39 – 47.

rights of individuals. It promotes fear and erodes trust and co-operation between the individual being tested and the health system, undermining prevention efforts. Voluntary counselling and testing services (VCT) protects people's rights by ensuring confidentiality, providing information about HIV transmission, and personalized discussions of an individual's risk, enabling people to make informed decisions about testing and their own risk.²⁰ In turn, this builds trust between those at risk and the health system, maximising the effectiveness of prevention programmes and ensuring access to care and support services where necessary.

Our experience to date in tackling the complexities of the global HIV/AIDS pandemic shows that failure to protect the human rights of people living with HIV/AIDS (PLHA) and those most vulnerable to HIV infection drives the spread and exacerbates the impact of HIV/AIDS. Poor and socially marginalised people are disproportionately vulnerable to HIV/AIDS and its consequences. Gender inequities impact upon the capacity of women and girls to protect themselves against HIV infection and magnify the impact of epidemic on women, particularly women living with HIV/AIDS. Stigmatization of people living with HIV/AIDS (PLHA) undermines their access to treatment, care and support, prevention information. The effects of this stigmatization manifests in discrimination against PLHA and those thought to be infected often affecting access to employment, housing, health and others services, in turn deepening the personal and social impacts of the epidemic. Stigmatization and denial of rights for populations particularly vulnerable to HIV infection, such as people who inject drugs, sex workers, men who have sex with men, limits access to prevention programmes, treatment, care and support health services, and undermines the capacity for community mobilization and empowerment, so critical to reducing vulnerability to infection.

A rights-based approach to public health action is vital to addressing the underlying conditions that make people vulnerable to HIV infection. Efforts to prevent the spread of HIV, and provide treatment, care and support to people living with HIV/AIDS are strengthened when human rights are protected. The protection and promotion of human rights lessens the adverse impacts of HIV/AIDS, and empowers individuals and communities to increase control over, and to improve, their own health.

2.3 Human rights principles

Value of using human rights

Human rights laws protect individuals and groups from actions that interfere with fundamental freedoms and human dignity.²¹ These rights seem intangible and abstract - lofty ideals - given the enormity and gravity of the global HIV/AIDS pandemic. This is particularly so in the developing world, where inequities drive the spread and exacerbate the impact of the disease. However, international human rights instruments do impose obligations on governments that ratify them to respect, protect and fulfil those rights. As such, they can be used to advocate for concrete action such as access to anti retroviral treatment and responding to stigma and discrimination.

Every country in the world is now party to at least one human rights treaty that addresses health-related rights, including the right to health and a number of rights related to conditions

²⁰ *AIDS, Health and Human Rights – An explanatory Manual*, provides a useful analysis of how HIV testing can protect the human rights, and in doing so support public health outcomes, see Part 2 pages 51 – 58 and pages 65 – 66.

²¹ *25 Questions and Answers on Health and Human rights*, Health and Human Rights Publication Series Issue No.1, July 2002, World Health Organization (WHO) at page 9.
<http://www.who.int/hhr/activities/publications/en/print.html>

necessary for health. This is invaluable in advocating for the realisation of these rights and in so doing, furthering the effectiveness of the HIV/AIDS response.²²

The principle of *progressive realization* of human rights acknowledges that the capacity of developing countries to ensure the full realization of these rights is often constrained by resource limitations. Nonetheless, this principle requires governments to take deliberate, concrete and targeted action towards that goal.²³ This does not necessarily require additional resources. Human rights principles can be used to advocate for improved access to services and programmes that already exist, to meet the needs of those most affected. So too, they can be used to advocate for more effective use of available resources.

A human rights framework must also guide NGOs in:

- the way they do their work²⁴
- the design, development and implementation of HIV/AIDS programmes and
- advocating for a legislative and public policy environment that supports effective programmes and protects the rights of PLHA and affected communities, enabling them to have control over, and improve their own health.²⁵

Key human rights principles relevant to HIV/AIDS

Human rights encompass civil, political, cultural, economic and social rights. It is clear that these rights are interrelated and interdependent. The right to health, for example, cannot be viewed in isolation from the right to education, housing and employment. The human rights principles outlined below identify the principles of particular relevance to the HIV/AIDS response.

NGOs commit to promoting human rights, in particular the following rights and freedoms articulated in international human rights law, in our work:

The right to health

All people have the right to the enjoyment of the highest attainable standard of physical and mental health. The International Covenant Economic, Social and Cultural Rights 1966 (ICESCR) provides that States Parties to the Covenant take steps to achieve the full realization of this right including prevention, treatment and control of epidemic, endemic, occupational and other diseases.²⁶

The Committee on Economic, Social and Cultural Rights, that monitors the ICESCR convention, has interpreted the 'right to health' to include not only timely and appropriate access to health care, but also the underlying determinates of health such as access to safe water, food, nutrition, housing and health-related education and information, including on sexual and reproductive health.²⁷ In April 2003, Commission on Human Rights passed a

²² 25 Questions and Answers on Health and Human rights, at page 14.

²³ International Convent on Economic, Social and Cultural Rights (ICESCR), Article 2(1); ICESCR General Comment 3 on the nature of State Parties obligations, Fifth Session 1990 (E/1991/23).

²⁴ See Operational principles Chapter 3

²⁵ The *HIV/AIDS and Human Rights International Guidelines* (See Section 2.7 Key Resources) apply human rights principles to the specific challenges of the HIV/AIDS response. The programme principles outlined in Chapter 4 include good practice principles to inform our advocacy efforts in each area of activity.

²⁶ ICESCR, article 12. As at November 2003, 148 member states (countries) have ratified (signed up to the obligations contained in) the ICESCR.

²⁷ In May 2000 the Committee adopted a General Comment on the right to health. General comments serve to clarify the nature and content of individual rights and governments obligations.

resolution that recognizes that access to HIV treatment is fundamental to progressively achieving the right to health and called on governments' and international bodies to take specific steps to enable such access.²⁸

The right to equality and non discrimination

The cornerstone of the Universal Declaration of Human Rights 1948 (UDHR) is that "All human beings are born free and equal in rights and dignity". This statement of equality of all human beings is closely linked to the right of all people to equal protection of the law and from discrimination.²⁹ For example, ICESCR prohibits discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status, which has the intention or effect of adversely affecting the equal enjoyment or exercise of the right to health.³⁰

The right to privacy

No-one shall be subject to arbitrary or unlawful interference with his/her privacy.³¹

The right to information

Everyone has the right to freedom of expression; this right includes freedom to seek, receive and impart information and ideas of all kinds.³²

The right of participation

Everyone has the right to active, free and meaningful participation.³³

The right to enjoy the benefits of scientific progress

Everyone has the right to enjoy the benefits of scientific progress and its applications.³⁴

[http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument)

²⁸ *Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria*, Commission on Human Rights resolution 2003/29, April 2003,

[http://www.unhchr.ch/Huridocda/Huridoca.nsf/\(Symbol\)/E.CN.4.RES.2003.29.En?Opendocument](http://www.unhchr.ch/Huridocda/Huridoca.nsf/(Symbol)/E.CN.4.RES.2003.29.En?Opendocument)

Also see *The protection of human rights in the context of HIV/AIDS*, Commission on Human Rights resolution 2003/47

<http://www.unhchr.ch/Huridocda/Huridoca.nsf/TestFrame/c73b1b5e18ebae52c1256d1f00419762?OpenDocument>

and the reports of the UN Special Rapporteur on the Right to Health:

[http://www.unhchr.ch/Huridocda/Huridoca.nsf/0/306eaaf7b4938ba9c1256dd70051435d/\\$FILE/N0356469.pdf](http://www.unhchr.ch/Huridocda/Huridoca.nsf/0/306eaaf7b4938ba9c1256dd70051435d/$FILE/N0356469.pdf)

[http://www.unhchr.ch/Huridocda/Huridoca.nsf/0/9854302995c2c86fc1256cec005a18d7/\\$FILE/G0310979.pdf](http://www.unhchr.ch/Huridocda/Huridoca.nsf/0/9854302995c2c86fc1256cec005a18d7/$FILE/G0310979.pdf)

²⁹ Universal Declaration of Human Rights (UDHR), article 1 and 7, International Convention on Civil and Political Rights 1966 (ICCPR) article 26, ICESCR article 2. The right of equality and non discrimination are also reflected in conventions which focus on the rights of women and children. See the Convention on the Elimination of All Forms of Discrimination Against Women 1979 (CEDAW) and the Convention of the Rights of the Child 1989 (CROC) respectively.

³⁰ See The Committee on Economic, Social and Cultural Rights *General Comment 14*, on the 'right to health' link in footnote 23.

³¹ ICCPR, article 17; CEDAW, article 16; CROC article 40.

³² UDHR, article 19; ICCPR, article 19.2; CEDAW, articles 10, 14 and 16; CROC, articles 13, 17 and 24.

³³ ICCPR, article 25; ICESCR, article 15; CEDAW, articles 7,8, 13 and 14; International Convention on the Elimination of All Forms of Racial Discrimination 1963 (CERD), article 5; CROC, articles 3, 9 and 12.

³⁴ ICESCR, article 15.

Freedom from torture

No-one shall be subject to torture or to cruel, inhuman or degrading treatment or punishment. In particular no-one shall be subjected without free consent to medical or scientific experimentation.³⁵

The right to work

Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to the protection against unemployment.³⁶

The right to education

Everyone has the right to education, directed to the full development of the human personality and the sense of its dignity and enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups.³⁷

The right to an adequate standard of living

Everyone has the right to an adequate standard of living, including adequate food, clothing, housing, and medical care and necessary social services.³⁸

2.4 Public health principles

NGOs commit to the following public health principles, applied within a rights-based framework:

Broad definition of health

The goal of public health is promoting the health of communities. A broad definition 'health' is required in order to take into account the social determinates of health, that impact so significantly upon the achievement of this goal. WHO defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.³⁹

Addressing population vulnerability

In order to promote the health of communities at a population level, it is critical to understand the array of factors which place particular populations at risk of HIV transmission or exacerbate the impact of HIV/AIDS including the social factors that underscore such vulnerability. Understanding the causes of vulnerability and developing service and programme responses that address the needs of specific communities is essential to an effective response to HIV/AIDS.⁴⁰

Evidence-based approaches

A thorough and comprehensive assessment of the needs of populations, in order to identify, understand and address population vulnerability, requires an evidence-based approach. Surveillance, monitoring and risk assessment, encompassing collection of data related to health status, epidemiological analysis and population health research provide an essential

³⁵ ICCPR, article 17 ; CROC, article 37.

³⁶ UDHR, article 23 ; ICESCR, articles 6.2 and 7(a).

³⁷ ICESCR, article 13 ; CROC, articles 19, 24, 28 and 33; CERD, article 5; CEDAW, articles 10 and 16 ; CROC, articles 19, 24, 28 and 33.

³⁸ UDHR, article 25; ICESCR, article 11.

³⁹ Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

⁴⁰ Addressing vulnerability in programmes and advocacy activities is considered in more detail at section 2.5.

evidence base for the development and delivery of effective HIV prevention programmes and services.

Prevention

Public health response to HIV encompasses three levels of prevention activities:

- primary prevention measures to prevent HIV transmission
- secondary prevention measures to ensure early detection, and successful management and treatment for people living with HIV/AIDS
- tertiary prevention measures to limit the further negative effects of HIV and increase the quality of life of people living with HIV/AIDS.

The public health model of primary, secondary, tertiary prevention is not the language that NGOs generally use. Nonetheless, this approach reflects what NGOs do, that is, that preventing HIV transmission, treatment care and support and impact mitigation are intrinsically linked.⁴¹

Community organization

Communities are a vital part of the HIV/AIDS response. Communities must be mobilized, informed, and empowered to “increase control over, and to improve, their health... through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavours and destinies”.⁴²

Healthy public policy

Public health seeks to influence the societal conditions which impact upon health by promoting the use of a scientific knowledge base and an understanding of the determinates of health to the development public policy, legislation and health systems that provide an enabling environment for effective responses to HIV/AIDS.

2.5 Addressing vulnerability

A right-based approach to public health action is vital to addressing the underlying conditions that make people vulnerable to HIV infection and magnify the impacts of HIV/AIDS for individuals and communities. In order to tackle the causes of vulnerability and to ensure the effective use of resources, priority must be given to populations who are at particular risk of HIV infection and those who bear a disproportionate burden of the impact of HIV/AIDS. In order to do so, an evidence-based approach is needed. Responses to HIV/AIDS need to be tailored to particular populations groups vulnerable to HIV infection and its’ consequences.

The specific populations that need to be given priority will vary from country to country, depending on the nature of the epidemic and the social, political, economic and cultural context. Priority populations will vary depending on the stage of the epidemic, whether there is high or low prevalence and whether the epidemic is widespread or concentrated within specific populations such as IDU or MSM. Key population priorities will invariable include PLHA and may include and women, children and young people with particular attention to the gender issues, sex workers and their clients, people who inject drugs (IDU), people with other

⁴¹ See Section 2.6 Comprehensive and integrated responses.

⁴² Ottawa Charter for Health Promotion, 1986. http://www.who.dk/AboutWHO/Policy/20010827_2

untreated sexually transmitted infections⁴³, and men who have sex with men (MSM), mobile populations such as migrant workers and incarcerated populations.

NGOs programmes are evidence-based and target those most vulnerable to HIV and its' impacts.

People living with HIV/AIDS

The impact of HIV/AIDS is felt most strongly, and understood most profoundly, by those living with HIV/AIDS. Central to responding effectively to HIV/AIDS must be meeting the complex ranges of needs of PLHA, including women living with HIV, across the range of activities outlined in Chapter 4 and involving PLHA at every level of the HIV/AIDS response.⁴⁴

Fundamental to achieving both is the need to address stigmatization of and discrimination against PLHA.

Women and girls

HIV/AIDS is not only driven by gender inequity – it entrenches gender inequality.⁴⁵ Women and girls are becoming increasingly vulnerable to HIV infection and bear the overwhelming burden of AIDS care, both informally in their families and communities and through the formal care sector.⁴⁶ Programmes need to recognize and respond to the variety of ways in which gender inequities expose women and girls to the risk of HIV infection, undermine women's access to services and programmes, and entrench the subordination of women. In many cultures unequal power in sexual relationships undermines the capacity of women and girls to exercise control over their sexual choices. One of the most serious manifestations of this inequity is gender based violence, which can expose women to HIV infection and fear of which can prevent them from protecting themselves against infection. Legislation often restricts women's right to own or inherit property, entrenching women's economic dependence on men, limiting their capacity to refuse sex or negotiate condom use.

A gendered approach to addressing these inequities needs to involve men and women and advocating for a legislative and policy environment that promotes the rights of women, in order to shift the dynamics that underscore women's subordinate position in society and sexual relationships. Gender inequities affect women's access to prevention information, education and appropriate treatment and care, both HIV and non HIV related.

Children and young people

Young people continue to make up a significant proportion of new infections each year, with 38% of people living with HIV/AIDS now under the age of 25.⁴⁷ Within the population of young people living with HIV/AIDS, particular subpopulations of young people are particularly vulnerable to HIV/AIDS infection, including young women and young men who have sex with men, young people who inject drugs, and sexually exploited children.⁴⁸ Many young people do not know how to protect themselves from HIV, and there are significant social and cultural

⁴³ Because exposure to HIV is considerably more likely to lead to infection when there is a concurrent untreated sexually transmitted infection present.

⁴⁴ Also see Operational principles – Section 3.4 Involvement of PLHA and affected communities and section 3.5 Access and Equity.

⁴⁵ Tallis, V. *Gender and HIV/AIDS: Overview Report*, Bridge Development and Gender, September 2002 at page 1.

⁴⁶ UNAIDS statistics indicate that in 1997 41% of PLHA were women, but 2001 the proportion increased to 50%. *Gender and HIV/AIDS: Overview Report*, at page 12 and page 24.

⁴⁷ *The Tip of the Iceberg: The Global Impact of HIV/AIDS on Youth*, The Henry J Kaiser Foundation, July 2002.

⁴⁸ For example, new infections among girls are as much as 5 to 6 times higher than for boys in some hard hit countries. *The Tip of the Iceberg: The Global Impact of HIV/AIDS on Youth*, at page 7.

barriers that impede the wide spread availability of appropriate sexual health and HIV and sex education for young people.

There is also a clear cycle of vulnerability in relation to orphans and children affected by HIV/AIDS. An estimated 14 million children have lost one or both parents to AIDS.⁴⁹ A holistic response including care in the community is needed to address their needs, which in turn can reduce their vulnerability to HIV infection.⁵⁰

Men who have sex with men (MSM)

Sex between men has been the predominate mode of transmission in some high and middle income countries. However, it is also factor in all HIV epidemics, but is often statistically hidden and officially denied.⁵¹ In recent decades there have been significant advances decriminalizing sex between men in many countries. Nonetheless, laws that criminalize or otherwise stigmatize or discriminate against MSM continue to drive the spread of HIV, by denying the rights of MSM and alienating them from prevention information and education. Programmes and services need be appropriate for and empower MSM to protect themselves from HIV infection and respond to discrimination. Advocacy efforts need to be directed to law reform and addressing the social stigmatization that increases the vulnerability of MSM.

Sex workers and their clients

The stigma associated with sex work in many countries around the world, creates significant barriers to sexual health and HIV prevention efforts among sex workers and their clients. While sex work has been decriminalizing in some countries, it remains illegal in many more. Even where knowledge about safe sex practices is high among sex workers, the power dynamics, entrenched by gender, legal and social inequities, makes putting that knowledge in to practice difficult. As such programmes, services and advocacy efforts need to be appropriate for sex workers and their clients. Strategies to promote an environment which supports HIV and other sexually transmitted infections (STIs), empower sex workers to stay on control of the transaction, exercise greater control over their health and address the societal conditions that increase their vulnerability.

People who inject drugs

HIV transmission through injection drug use accounts for approximately 10% of HIV infections globally and is a dominate factor driving HIV infection rates in many countries around the world.⁵² A comprehensive range of services and programmes are needed in order to respond effectively to the harms associated with injection drug use including education programmes that reduce the risk of HIV infection among those who inject drugs (as well as those that deter people from drug use), access to clean needles and syringes, drug treatment programmes, and health care services appropriate for the needs of people who inject drugs. The illegality and stigma associated with injection drug use, invariably leads to discrimination against people who use drugs.⁵³ Commonly this results in alienating people who use drugs from access to health and related support services, leading to negative health outcomes for those who inject and undermining effective prevention. Concerted efforts must be made to ensure support for and availability of the full complement of services and programmes that reach and involve people who inject drugs.

⁴⁹ *Report on the global HIV/AIDS epidemic*, UNAIDS, July 2002 at page 133.

⁵⁰ See Impact Mitigation, section 4.4.

⁵¹ Data from countries as diverse as India, Mexico, and Thailand confirm that men who have unprotected sex with men, also have unprotected sex with women, *Report on the global HIV/AIDS epidemic*, at page 91 – 92.

⁵² *Drug use and HIV/AIDS*, UNAIDS, June 2001.

⁵³ *HIV and AIDS - related stigmatization, discrimination and denial: forms, contexts and determinants*, UNAIDS, June 2000, search by title <http://www.unaids.org/EN/other/functionalities/Search.asp>

Context that heighten vulnerability

It is also important to note that particular contexts also heighten vulnerability to HIV infection and its impact on individuals and communities. The conditions that arise in complex emergencies such as armed conflict and natural disasters – social instability, poverty, displacement of populations, gender based violence – are also the conditions which maximize spread HIV. There is increasing recognition that HIV/AIDS related dimensions of complex emergencies require special attention.⁵⁴

Correctional facilities, such as adult gaols and juvenile detention centres are also a setting in which a combination of factors heightens vulnerability to HIV infection. This is commonly characterised by concentrated populations of people living with HIV, where injecting drug use, tattooing, voluntary and forced sex commonly occur, in an environment where there is limited and often no access to the means of preventing the spread of HIV and inadequate HIV prevention education programmes.⁵⁵ This has significant ramifications not only for inmates themselves but also for the families and communities to whom they return, often after relatively short terms of imprisonment. Attempts to reduce drug use by mandatory drug screening have often had counterproductive results.⁵⁶ Programmes need to address the specific risks of HIV infection in prisons and meet the often complex health needs of prisoners, including those living with HIV/AIDS.

2.6 Comprehensive and integrated responses

Good Practice Principles

HIV/AIDS programmes are integrated within prevention – care continuum

Chapter 4 provides good practice principles in prevention, treatment, care and support, addressing stigma and discrimination, impact mitigation and scaling up. Each of these areas of activities encompass the component parts of a comprehensive response, rather than as separate and distinct responses. Prevention and treatment, care and services need to be effectively integrated as a 'continuum', informed by a rights-based approach. For example, VCT services need to be linked to treatment, care and support services and conducted in a manner that ensures that people's rights are protected in order to maximise access to testing for those most vulnerable to HIV infection and ensure that PLHA they have access to treatment, care and support they need as well as the necessary information, skills and support to prevent transmission to others.

Efforts to expand access to ARVs has also been accompanied by a better understanding of the ways in which access to treatment saves lives, but also assist in reducing the stigma associated with HIV/AIDS infection and strengthens prevention efforts. Maximising access to life-saving drugs will improve the health status of many people living with HIV/AIDS, enhancing their well being and capacity to participate in society, provide new incentives for people to know their HIV status, as well improving the infrastructure for voluntary testing and counselling, thereby strengthening the reach of prevention programmes and access to treatment care and support for PLHA.

⁵⁴ See Section 2.6 Key resources

⁵⁵ *Report on the global HIV/AIDS epidemic*, at page 97 – 98.

⁵⁶ Research in to mandatory screening in UK prisons found that inmates shifted from smoking marijuana which is detectable in urine for several weeks, to inject heroin which is detectable from urine after one to two days; *Report on the global HIV/AIDS epidemic*, at page 97.

HIV/AIDS advocacy programmes are an integrated part of the HIV/AIDS response

Advocacy is a method and a process of influencing decision makers and public perceptions about an issue of concern, and mobilising community action to achieve social change, including legislative and policy reform, to address the concern.

Within each area of activity considered in Chapter 4, the good practice principles outline the range of services and programmes needed to provide a comprehensive response to HIV/AIDS, including advocacy programmes that needed to be an integral part of a comprehensive response. Advocacy initiatives designed to promote law and policy reform are critical to building an environment that supports the rights of PLHA and affected communities, and is conducive to mobilising communities and maximising the effectiveness of programmes. For example, there often are legal and societal impediments to the provision of services and programmes designed to meet the needs of people who inject drugs, men who have sex with men, and sex workers and their clients. It is critical that NGOs make a concerted effort to address these impediments and in so doing advance the rights of people living with HIV/AIDS and affected communities. The *Declaration of Commitment on HIV/AIDS*, international human rights instruments and the International Guidelines on HIV/AIDS and Human Rights provide a blueprint for reform and invaluable tools for advocating national action.⁵⁷

NGO foster partnerships between HIV/AIDS specialist NGOs, and health, development and human rights NGOs

Partnerships between HIV/AIDS specialist NGOs and NGOs working to address a wide range of health, development and human rights concerns are vital in order to achieve a comprehensive, integrated and cohesive response to HIV/AIDS.

In recent years there has been an increasing awareness of and strategies to address:

- the long term ramifications of the pandemic and the impact of HIV/AIDS on development efforts
- the specific vulnerabilities that arise as a result of armed conflict and natural disasters and
- the human rights dimensions of vulnerability to HIV/AIDS and the impact of HIV/AIDS on individuals and communities.

For example, humanitarian interventions are incorporating HIV/AIDS considerations in to programmes designed to address water sanitation, food security and access to basic health care and nutritional needs of PLHA and their communities.⁵⁸ So too, development initiatives designed to improve access to education, sustainable livelihoods, build community and health infrastructure make an important contribution to addressing vulnerability to HIV/AIDS and alleviating the impact of HIV/AIDS. While many development NGOs are actively involved in provision of HIV prevention, and treatment, care and support and impact mitigation programmes, they also aim to address the underlying causes of vulnerability. Programmes to improve access to education, address poverty and gender based violence for example, are a vital part of responding effectively to HIV/AIDS. Human rights NGOs are active in promoting a rights approach to addressing HIV/AIDS, as well as working to advance human rights more

⁵⁷ See Section 2.7 Key Resources.

⁵⁸ See for example, Guidelines for interventions in emergency settings, see Key Resources and *Community home-based care for people living with HIV/AIDS*, International Federation of Red Cross and Red Crescent Societies, http://www.ifrc.org/cgi/pdf_pubs.pl?health/hivaids/hbc.pdf

broadly, such as promoting gender equity, which in turn is invaluable to promoting an environment that enables effective responses to HIV/AIDS.

As a result there are an increasing range of players now taking an active role in responding to the broad ranging implications of HIV/AIDS pandemic. HIV/AIDS specialist NGOs can bring significant expertise to enhancing development, humanitarian and human rights efforts. So too, development, humanitarian and human rights NGOs bring a wealth of experience and capacity to responding to the underlying causes of vulnerability to HIV/AIDS infection and impacts of HIV/AIDS. These developments underscore the need to develop collaborative working partnerships in order to build on and enhance the capacity of HIV/AIDS specialist NGOs and NGOs working to address HIV/AIDS, and the wider range of health, development and human rights concerns that underpin a comprehensive response to the complexities of the HIV/AIDS pandemic.

2.7 Key resources

Declaration of Commitment on HIV/AIDS, United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in 25 – 27 June 2001,
<http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html>

Advocacy Guide to the Declaration of Commitment on HIV/AIDS, ICASO, October 2001.
<http://www.icaso.org/icaso/ungass/advguidedectncomit.htm>

AIDS, Health and Human Rights – An explanatory Manual, International Federation of Red Cross and Red Crescent Societies and Francois-Xavier Bagnoud Center for Health and Human Rights Harvard School of Public Health, 1995.

HIV/AIDS and Human Rights International Guidelines, Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations New York and Geneva 1998,
www.unaids.org/publications/documents/human/law/hright2e.doc

The above guidelines have been revised to reflect new standards in HIV/AIDS treatment and the evolving international law on the right to health. See *HIV/AIDS and Human Rights International Guidelines – Revised Guideline 6 – Access to prevention, treatment, care and support*, OHCHR and UNAIDS, March 2003, www.unhcr.ch/hiv/g6.pdf

NGO Summary of the International Guidelines on HIV/AIDS and Human Rights and An Advocate's Guide International Guidelines on HIV/AIDS and Human Rights, the International Council of AIDS Service Organisations (ICASO), 1999.
<http://www.icaso.org/icaso/docs/hivaidsguidelnsumm.htm>

HIV/AIDS and Human Rights: How have they been applied? An assessment of national responses in improving access to HIV/AIDS Treatment within the framework of the International Guidelines on HIV/AIDS and Human Rights, May 2002, ICASO,
<http://www.icaso.org/icaso/docs/JFAP%20-%20Web.pdf>

Audit tool for measuring national compliance with *International Guidelines on HIV/AIDS and Human Rights*, to <http://www.ancahrd.org/pubs/index.htm>, (xx to be amended when Helen Watchirs book published later in 2004) and references to application of tool in Australia, Canada and Cambodia when reports available.

IPPF Charter on Sexual and Reproductive Rights, International Planned Parenthood Federation (IPPF), 1996. <http://www.ippf.org/charter/index.htm> (xx check whether hard copy received is updated version)

Advocacy Guide for HIV/AIDS, June 2001, and *Advocacy Guide to Sexual and Reproductive Health Rights*, July 2001, IPPF, <http://www.ippf.org/resource/index.htm#Documents>

Advocacy in Action – A Toolkit to Support NGOs and CBOs Responding to HIV/AIDS, International HIV/AIDS Alliance, June 2002, <http://www.aidsalliance.org/eng/>

Advocacy tools and guidelines: Promoting policy change manual, Care International, 2001 <http://www.careusa.org/getinvolved/advocacy/tools.asp#english>

Ottawa Charter for Health Promotion, 1986.
http://www.who.dk/AboutWHO/Policy/20010827_2

Bring Rights to Bear: An Advocate's Guide to Work of UN Treaty Monitoring Bodies on Reproductive and Sexual Rights, Center for Reproductive Rights, 2002.
http://www.crlp.org/pub_bp_tmb.html

Resources to support programming for specific populations are also provided within each area of activity considered in Chapter 4.

Gender and HIV/AIDS: Overview Report,
<http://www.ids.ac.uk/bridge/reports/CEP-HIV-reportw2.doc> and *Gender and HIV/AIDS: Supporting resources collection*, <http://www.ids.ac.uk/bridge/reports/CEP-HIV-SRw2.doc>
Bridge Development and Gender, September 2002.

Integrating Gender into HIV/AIDS Programmes, WHO, 2003.
http://www.who.int/gender/hiv_aids/hivaids1103.pdf

Women And HIV/AIDS: The Barcelona Bill Of Rights, July 2002,
<http://www.saathii.org/other/BarcelonaBillOfRights.html>

Positive Development: Setting up self-help groups and advocating for change. A manual for people living with HIV, Global Network of People Living with HIV/AIDS (GNP+), 1998,
<http://www.gnpplus.net/programs.html>

What religious leaders can do about HIV/AIDS: Action for Young Children and Young People, UNICEF, World Council for Religions for Peace and UNAIDS, November 2003,
http://www.unicef.org/publications/index_19024.html

Young people and HIV/AIDS: Opportunity in crisis, UNICEF, UNAIDS and WHO, 2002,
http://www.who.int/hiv/pub/prev_care/youngpeople/en/

Working with men, responding to AIDS: Gender, sexuality, and HIV – A case study collection, The International HIV/AIDS Alliance, 2003, <http://www.aidsalliance.org/eng/>

Humanitarian Charter and Minimum Standards in Disaster Response, The Sphere Project, 2nd Edition, 2004.

Guidelines for interventions in emergency settings, Inter-agency Standing Committee,
<http://www.humanitarianinfo.org/iasc/IASC%20products/FinalGuidelines17Nov2003.pdf>

Chapter 3 – Operational Principles

3.1 Governance

NGOs have transparent governance and are accountable to their communities / constituencies.

Governance bodies need to have clear written policies, which are effectively implemented in practice, addressing the following:

- appointment and termination of members of the governing body
- identifying and mitigating conflicts of interest
- defined roles and responsibilities of the governing body, both individually and jointly, including strategic planning, financial probity and oversight of quality assurance
- guidance about how the strategic responsibilities of the governing body are delegated to operational management
- accountability and reporting arrangements both internally, and to donors, NGO partners and communities where applicable
- mandate from communities, whether geographical or population based, where a Supporting NGO provides services, programmes and undertakes advocacy initiatives to a defined community, such as through general elections, designated community representatives position on the governance body.

3.2 Organisational mission & management

NGOs have a clear mission, supported by strategic objectives that are achieved through good management.

NGOs need to have a clear statement of mission, supported by statement of values that underpin the organization's work.⁵⁹ Effective strategic and operational planning, human resources and financial systems are essential to support the achievement of the organization's mission. Strategic objectives, for a defined period, need to be informed by an assessment of the HIV/AIDS situation(s), the range of institutional responses that already exist, and the organizational capacity, in order to determine what gaps in programming exist and whether the organization is best placed to address them. An operational planning is needed to support the achievement of strategic objectives, including clear timeframes, performance indicators, allocation of financial and human resources needed to meet these indicators, and a strategic approach to human resources management. Operational plans need to be linked to programme plans and individual work plans.⁶⁰

NGOs value, support and manage their human resources

Strategic and operational plans need to provide a strategic approach to human resources management including:

- explicitly valuing staff and volunteer contributions
- allocating sufficient human and financial resources to achieve the objectives set and
- clear management responsibility for staff and volunteer support, development and wellbeing.

⁵⁹ See Also Section 2.1 Core beliefs and values.

⁶⁰ Also see Good Practice Principles regarding human resources management and section 3.3 programme planning below.

Human resources policies and procedures need to be effectively implemented to ensure:

- fair, transparent and effective recruitment and selection of staff and volunteers, including equal employment opportunity⁶¹
- consistent and clear guidance to staff regarding roles and responsibilities including job description and development and regular review of staff work plans
- assessment of human resource capacity
- organizational learning by supporting staff and volunteers training and development
- security, safety and health of staff and volunteers, including promoting a non-discriminatory workplace, advocating for health insurance products covering HIV/AIDS-related and generating the necessary resources, organisational commitment and policy to facilitate access to ARVs for staff and volunteers living with HIV/AIDS.^{62 63}

NGOs manage their financial resources in an efficient, transparent and accountable manner.

Financial control systems are needed to support the achievement of strategic objectives by:

- systemic preparation of budgets linked to strategic, operational and programmes plans
- internal control systems that ensure consistent and reliable financial information, that complies with legal requirements
- internal accounting systems provide regular financial reports, in a consistent, accessible format to enable monitoring of programmes spending against budget allocation
- an efficient grant programming system and provision of finance and administrative technical support, where funding is provided to partner NGOs
- regular financial reporting to management and governing board, donors and statutory reports where required and
- annual financial auditing of accounts.

3.3 Programme planning & evaluation

NGOs select appropriate partners in a transparent manner.

Transparent selection systems are needed to ensure identification of partner NGOs that:

- are the most appropriate to achieve the programme objectives
- have the necessary financial and programmatic capacity to manage the activities or can be supported to develop financial and programmatic capacity
- are appropriate to work with identified beneficiary communities, including assessment of community credibility.

⁶¹ Consistent with good practice principles regarding the meaningful involvement of PLHA and affected communities in all aspects of the response, attention needs to be paid to implementing human resource policies that promote inclusion of and commitment to the employment of PLHA and affected communities, including affirmative action strategies that address underlying obstacles to meaningful participation and acknowledge the value of PLHA and affected communities involvement in a wide range of roles, including design and delivery of programmes.

⁶² See for example, The International Federation of Red Cross and Red Crescent Societies advocacy efforts <http://www.ifrc.org/docs/news/pr03/7203.asp> and workplace treatment programme, the Masambo fund, http://www.ifrc.org/what/health/hivaids/treatment_masambo.asp

⁶³ See Key Resources for relevant human resources management and work place policy resources.

NGOs plan, monitor and evaluate their programmes for effectiveness and in response to community need.

Programme plans need to set clear objectives, timeframes, performance indicators, reporting requirements, and allocate financial and human resources needed to meet the programme objectives.

Programme objectives and priorities need to be evidence-based drawing on:

- relevant epidemiological, social and behavioural research data
- relevant programme evaluations findings and
- assessment of community need, including mapping of available services and programmes to determine gaps in types of programmes and services or gaps in meeting the needs of particular communities vulnerable to HIV/AIDS
- build on community strengths

Supporting NGOs' programme plans needs to include the technical support to partner NGOs:

- on HIV/AIDS related issues as specific programmes require
- programming design, implementation, monitoring and evaluation
- organizational development including strategic planning, financial and administrative systems, human resource strategies to promote effective management of staff and organizational learning.

Programme plans need to incorporate monitoring and evaluation in to the planning cycle by:

- setting programme objectives at the outset that are appropriate for monitoring and evaluation of the programme
- monitoring indicators are developed and used to guide systematic collection of information, including qualitative evidence, over time to assess whether the programme is proceeding according to plan, and whether there are obstacles to doing so that need to be addressed
- evaluation of the programmes to assess the quality, efficiency and effectiveness of the programme and
- utilizing programme evaluation findings to inform future programmes or adjustments to the existing programmes over time.

Efforts to better understand and improve the effectiveness of HIV prevention, treatment, care and support services and programmes have produced an impressive body and knowledge and resources to inform monitoring and evaluation.⁶⁴ Monitoring and evaluating the impact of advocacy efforts is comparatively underdeveloped.⁶⁵ Advocating for legal, policy and social change often involves long term strategies, in partnerships with other organizations, often with multiple targets for advocacy efforts, including political leaders, media institutions, community leaders, governments, and public and private sector agencies. The causality between advocacy efforts and law and policy changes and changes in social norms is often difficult to measure.

NGOs need to plan and measure the impact of advocacy programmes by:

- setting clear objectives about what legal, policy or social change is being sought
- identifying target audiences for advocacy efforts to achieve the objectives

⁶⁴ See some key resources in section 3.6. A wide range of resources are also available on the UNAIDS website <http://www.unaids.org/en/in+focus/monitoringevaluation.asp>

⁶⁵ See discussion of integration of advocacy efforts within prevention, treatment care and support, impact mitigation, and anti-discrimination work, section 2.6 and good practice principles in advocacy in each of the areas of activity considered in Chapter 4.

- identifying and developing strategic partnerships that can lend support to achieving the objectives
- monitoring information is used to track the external environment to determine what factors are impacting on advocacy outcomes including media reports, policy statements of target audience, meeting discussions
- an assessment is made about the variety of evaluation methods needed, that utilize the information gathered, in order to assess the extent to which advocacy efforts have: affected awareness about the issues; influenced the organizations credibility as an advocate; made a contribution to debate; changed laws and policy; influenced the attitudes or beliefs of opinion leaders and had any impact on the lived experiences of PLHA and affected communities
- evaluation methods examines the effectiveness of processes used, including effectiveness of partnerships, involvement of PLHA and affected communities and organizational advocacy capacity and
- evaluation methods examine the views of target audience, programme implementers, beneficiaries of advocacy efforts about the processes used and impact of advocacy activities.⁶⁶

3.4 Involvement of PLHA and affected communities

NGOs foster active and meaningful involvement of PLHA and affected communities.

The guiding principles outlined in Part 2 include the right to active, free and meaningful participation.⁶⁷ In giving effect to this right in the context of the HIV/AIDS response, NGOs recognize that the meaningful involvement of PLHA and affected communities also makes a powerful contribution to the HIV/AIDS response by empowering people living with HIV/AIDS and affected by HIV/AIDS to contribute their lived experiences. In turn this contributes to reducing stigma and discrimination and increasing the effectiveness and appropriateness of programmes.

PLHA and affected communities need to be involved in a variety of roles at different levels in NGOs, including as decision makers on governing boards, as providers of programmes and services, as campaigners in advocacy activities and as advisors in programme design, implementation and evaluation, as speakers and participants in meetings and conferences. In addition to fostering involvement within their own organizations, NGOs also need to advocate for funding of PLHA and affected communities' organizations to ensure PLHA and affected communities have the resources to build capacity and empower others with their own networks.

When determining who to involve in different aspects of the NGOs work, consideration needs to be given to both the expertise that involvement will bring to the particular role and the ways in which that involvement is supported by the organization. In order to address vulnerability, and meet the needs of specific communities at particular risk of HIV infection, involvement of sex workers, MSM, young people, PLHA must be an integral part of programme development, implementation and evaluation for prevention programmes to meet the particular needs of these communities. So too, design, implementation and evaluation of care, support and treatment programmes activity should involve PLHA, partners and carers of PLHA.

⁶⁶ Useful resources include: *Advocacy tools and guidelines: Promoting policy change manual*, Care International, 2001 <http://www.careusa.org/getinvolved/advocacy/tools.asp#english> and Bond Guidance Notes series on monitoring and evaluating advocacy, <http://www.bond.org.uk/advocacy/guideval.html>

⁶⁷ See Section 2.3, the right to participation.

Design note: Insert UNAIDS document diagram – pyramid of involvement of PWHA (page 3)

How meaningful involvement is fostered will depend upon the specific role concerned, however, consideration is given to:

- clearly defining the role and its associated responsibilities
- assessing what a particular role requires, the capacity of individuals to fulfil the role, and provision of the necessary organizational support, including financial, to enable meaningful involvement
- ensuring organizational policies and practice provide timely access to information to enable participation, preparation, input, before programmatic and policy decisions are made and
- workplace policies and practices that create an environment which support the involvement of PLHA and affected communities.⁶⁸

3.5 Access and Equity

NGOs programmes are non-discriminatory, accessible and equitable.

Ensuring programmes are equitable, accessible and non-discriminatory is one of the ways that NGOs can demonstrate their commitment to the human rights principles set out in Chapter 2. Equity in programming requires that resources are allocated and programmes are developed in response to identified community need.⁶⁹

The term 'discrimination' is used when people are treated adversely, either by treating them the same, when their needs are different, or treating them differently where they should be treated the same.⁷⁰ Programmes and services need to be accessible to all those who require access, with particular attention to how to market and deliver programmes that reach communities who are marginalized.

Access to programmes and services need to be supported by workplace policies and practices that ensure:

- the rights of PLHA and affected communities are respected⁷¹
- the rights of service users are clearly articulated and promoted to communities, particularly those most marginalized
- that people have access to appropriate information to enable them to understand the implications of participation, and freely decide whether or not they wish to participate⁷²
- the rights of service users are supported by user friendly complaints mechanisms

⁶⁸ See for example, *Working Positively: A guide for NGOs managing HIV/AIDS in the workplace*, key resources.

⁶⁹ Reflected in Good practice principles in Programme planning and evaluation, Section 3.3.

⁷⁰ ICESCR prohibits discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health. See The Committee on Economic, Social and Cultural Rights *General Comment 14* on the 'right to health'.

[http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument)

⁷¹ Implementing the right to equality and non discrimination discussed in Section 2.3. Reflected in Good practice principles regarding building organizational capacity to address stigma and discrimination considered in section 4.3 and Good practice principles in addressing vulnerability, Section 2.5.

⁷² This is an expression of the right to information, see Section 2.3.

- that people's confidentiality is protected thereby promoting an environment where PLHA and affected communities are confident to access information and programmes and actively participate in the HIV/AIDS response⁷³ and
- PLHA and affected communities are actively involved in a wide range of roles within the organization.

The rights of PLHA and affected communities include their sexual and reproductive rights. In order to ensure programmes are accessible and appropriate for those at risk of STIs and HIV, they need to be informed by a rights framework which embodies the right to:

- have control over one's own body
- make decisions about one's sexuality
- to freely chose to have sex
- have sexual enjoyment
- protect oneself from the consequences of sex, such as pregnancy, STIs and HIV
- have access to non-judgmental, responsive services that enable people to have control over their sexual and reproductive health.⁷⁴

Accessibility of services alone is insufficient to respond to the diverse needs of PLHA and affected communities. Programmes that are generic in nature, assuming that communities are reached by the same approach or type of service, often reflect and entrench societal inequities. To ensure access and equity, programmes need to be tailored to meet the particular needs of PLHA and affected communities. For example, HIV prevention programmes, targeting men and women, need to address gender stereotypes, norms, attitudes and practices in order to address underlying gender inequities that increase women and girls vulnerability to HIV infection. So too, gender inequities that impede access to services and programmes for women, including those living with HIV/AIDS, need to be understood and addressed. Programmes need to be specifically designed to meet the needs of vulnerable populations including young people, MSM, sex workers, injecting drug users, and prisoners. Programmes need to be respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements. Equity of access to services and programmes is best achieved by actively involving PLHA and affected communities not only in the design and delivery of programmes, but in a wide variety of roles within NGOs.⁷⁵

3.6 Key resources

Resources, particularly in relation to involvement of PLHA and affected communities in specific aspects of the HIV/AIDS response are also provided in each area of practice considered in Chapter 4.

HIV/AIDS NGO/CBO Support Toolkit, CD Rom and Website, International HIV/AIDS Alliance, 2nd Edition, December 2002, <http://www.aidsalliance.org/ngosupport/>

Code of good practice in management and support of aid personnel, People in Aid, 2nd Edition, 2003. <http://www.peopleinaid.org/>

Working Positively: A guide for NGOs managing HIV/AIDS in the workplace, UK Consortium on AIDS and International Development, December 2003. Also provides a good list of

⁷³ This is an expression of the right to privacy, see Section 2.3.

⁷⁴ *Gender and HIV/AIDS: Overview Report*, Bridge Development and Gender, September 2002 <http://www.ids.ac.uk/bridge/reports/CEP-HIV-reportw2.doc>

⁷⁵ See Involvement of PLHA and affected communities, section 3.4.

resources available on line.

<http://www.aidsconsortium.org.uk/Workplace%20Policy/workplaceguide.htm>

Developing HIV/Workplace and Medical Benefits Policies – Draft Summary, International HIV/AIDS Alliance, December 2003,

http://www.aidsalliance.org/_res/training/care/Medical_benefits.pdf

Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries: A Handbook for Programme Managers and decision makers, FHI, search by title

<http://www.fhi.org/en/HIVAIDS/Publications/index.htm>

From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA), UNAIDS Best Practice Collection, September 1999, <http://www.unaids.org>, search using title name.

The involvement of people living with HIV/AIDS in community based prevention, care and support programmes in developing countries, Horizons and the International HIV/AIDS Alliance, July 2003

Positive Development: Setting up self-help groups and advocating for change. A manual for people living with HIV, Global Network of People Living with HIV/AIDS (GNP+), 1998,

<http://www.gnpplus.net/programs.html>

A Positive Woman's Survival Kit, ICW. An online English version of this resource is currently being developed. Please note, only Spanish is currently available on <http://www.icw.org/tiki-index.php?page=Publications>

Greater involvement of PLHA in NGO service delivery: Findings from a four-country study, International HIV/AIDS Alliance, summary of the report, published by Horizons, July 2002; and

Children's Participation in HIV/AIDS Programming, International HIV/AIDS Alliance, December 2002. Above three documents available at <http://www.aidsalliance.org/eng/>

A vital partnership: The work of GNP+ and the International Federation of Red Cross and Red Crescent Societies, UNAIDS Best Practice Collection, 2003. xx add web reference to UNAIDS website when document is available online.

Chapter 4 – Programming Principles

4.1 HIV prevention

Overview

There is an impressive body of evidence and experience to guide effective HIV/AIDS prevention. Given that prevention efforts reach fewer than one in five of those at risk, one of the most significant challenges we now face is ensuring that this knowledge is consistently applied, in scaling up prevention efforts to reach the millions of people at risk of HIV infection world wide^{76 77}

It is clear that multiple prevention approaches must be employed in combination in order to:

- support individual behaviour change
- change the social norms regarding risk behaviours and
- address the societal impediments to effective HIV prevention.⁷⁸

Good Practice Principles

HIV prevention is integrated within sexual health, HIV testing, treatment, care and support and harm reduction programmes.

Prevention programmes can be strengthened by integration within:

- sexual and reproductive health programmes including STI prevention and treatment
- antenatal services to enable pregnant women access to VCT, and ensure the HIV positive pregnant women have appropriate information treatment, birthing and feeding practices to reduce the risk of HIV transmission to their child and access to HIV treatment, care and support to address their own health needs
- harm reduction programmes including NSPs (needle and syringe programmes), drug treatment programmes and related health services for injecting drug users and
- HIV treatment, care and support programmes.

It is well recognised that access to VCT is critical to enabling people to initiate or maintain behaviours to prevent acquisition or further transmission of HIV, reduce risks of mother to child transmission (MTCT), as well as diagnose those living with HIV and enable access to treatment, care and support services.⁷⁹

The synergies between prevention and treatment need to be harnessed as the global commitment to providing access to ARVs to the millions of people in the developing world becomes a reality. As ARVs become more widely available, there will be a greater incentive to test for HIV. To deliver ARVs to millions will require a massive increase in the provision of VCT services and investment in health infrastructure will be needed to enable delivery of

⁷⁶ *Access to HIV Prevention*, Global HIV Prevention Working Group, May 2003.

⁷⁷ Also see Section 4.5, Good practice principles in Scaling up.

⁷⁸ *Global Mobilization of HIV Prevention: A Blueprint for Action* pages 8 – 18, in key resources below.

⁷⁹ Report on the global HIV/AIDS Epidemic, UNAIDS, 2002 pages 122 – 124. Also see Good practice principles regarding VCT services in Section 4.2 Treatment, care and support.

ARVs.⁸⁰ This in turn will provide new opportunities for prevention interventions to be integrated within treatment and care services.⁸¹

Sexual and reproductive health services and programmes are essential to reducing the risks of HIV transmission and ensuring women have their health needs met. Identifying and treating STIs reduces the risk of transmitting and acquiring HIV.^{82 83} Integration of family planning, maternal and child health, antenatal care, and prevention and management of STIs and HIV provide a holistic approach to sexual and reproductive health that are appropriate for and reach particular populations at risk. This is particularly so for women, who are likely to access such services for a range of health needs, but who may not perceive themselves to be at risks of HIV infection, but are nonetheless may be exposed to HIV by their partner. Prevention of MTCT needs to go beyond specific interventions such as ARVs, replacement feeding and caesarean deliveries, to include prevention among young women, quality prenatal care, access to contraception and counselling about reproductive health options, and treatment, care and support for women living with HIV/AIDS. A holistic approach to sexual and reproductive health is also likely to meet the range of health needs of sex workers. It is crucial that sexual and reproductive health services are accessible and appropriate for sex workers.

NGO HIV prevention programmes use a range of methods to meet the variety of needs of individuals and communities.

Prevention programmes that ensure that the whole spectrum of prevention options are available to those most at risk, including access and use of condoms and sterile injecting equipment, have been shown to substantially reduce new HIV infection throughout the world.^{84 85}

Comprehensive HIV prevention programmes need to include:

- easily accessible information about the risks of HIV infection and means of prevention in relation to these risks
- tailored education programmes, including counselling, discussion groups, peer support activities to enable people to develop the skills and support to reduce their risk of infection by adopting and sustaining safer sex, safer injecting practices in real life situations and/or make informed decisions about treatment, birthing and feeding practices to reduce the risk of MTCT
- access to and information about the use of commodities for prevention - male and female condoms, and/or sterile injecting equipment and

⁸⁰ *Treating 3 million by 2005: Making it Happen*, WHO, December 2003.

<http://www.who.int/3by5/publications/documents/en/3by5StrategyMakingItHappen.pdf>

⁸¹ See for example: *Integrating HIV voluntary counselling and testing into reproductive health settings: Stepwise guidelines for programme planners, managers and service providers*, IPPF and UNFPA, February 2004, xx add web ref when guidelines finalized.

⁸² WHO estimates that over 300 million people are infected each year with curable STIs, a significant proportion of which occur among young people. The presence of such infections during unprotected sex magnifies the risk of HIV transmission as much as tenfold. *Report on the global HIV/AIDS epidemic*, UNAIDS, 2002.

⁸³ See also testing and treatment Good practice principles.

⁸⁴ Research indicates that comprehensive programmes are more effective in reducing HIV risk than programs that only promote abstinence: Jemmott, J. et al *Abstinence and Safer Sex HIV Risk Interventions for African American Adolescents: A Randomized Controlled Trial*, JAMA 1998, 1529 – 1536, cited in *Global Mobilization of HIV Prevention: A Blueprint for Action* and discussion pages 8 – 18; also see WHO *Evidence for Action* series (See Key resources)

⁸⁵ The need of comprehensive prevention programmes is reflected in paragraphs 47 – 54 of the *Declaration of Commitment on HIV/AIDS*. See Section 2.7 Key Resources.

- access to voluntary testing and counselling, linked to, STI, harm reduction programmes, and HIV/AIDS treatment, care and support where necessary⁸⁶ and
- social marketing programmes that influence community norms to support and sustain safer behaviours.

Tailored resources and commodities need to be provided for those who cannot afford or access them including:

- condoms and lubricant: what choices exist locally; how to use them effectively; alternatives such as the female condom⁸⁷
- sterile injecting equipment, or in their absence commodities for effective sterilisation
- commodities are provided through outreach programmes to sites and settings where sexual and drug taking activity occurs, such as commercial sex premises, non-commercial outdoor sites where people meet to make sexual encounters and places where drug injecting commonly occurs
- targeted resources accompany commodities distribution to ensure their effective use and promote access to HIV prevention, testing and treatment services.

HIV prevention information education and communication (IEC) programmes should:

- prioritise interactive personalised interventions, such as counselling and peer support to equip people with the necessary understanding and skills to protect themselves in real-life situations and
- be based on individual assessment of their particular needs in relation to HIV prevention, clarification of any misunderstandings about HIV transmission and risk behaviours, addressing difficulties they may have in putting risk reduction strategies in to practice in their lives.

HIV prevention programmes need to enable people to make a realistic assessment of the risks in their own lives, informed decisions and develop the skills necessary to adopt practices appropriate for them. This means HIV prevention programmes must be comprehensive. In relation to injecting drug use this may include abstaining from, stopping or reducing drug use, accessing drug treatment, utilizing non-injecting methods of drug use and effective use of sterile injecting equipment. In relation to sexual behaviour this may mean abstaining from sexual activity, reducing the number of sexual partners, delaying commencement of sexual activity, deciding to be faithful to one partner, accessing treatment for STIs and using condoms to protect themselves from HIV infection and other STIs.

Despite the lack of evidence to support the effectiveness of abstinence only programmes, funding is increasingly being directed to them, particularly for young people.^{88 89}

⁸⁶ Detailed good practice principles in relation to each of these elements are considered in this section.

⁸⁷ Research demonstrates that condoms, when used consistently and correctly, are highly effective in preventing transmission of HIV. CDC, National Center for HIV, STD and TB prevention, <http://www.cdc.gov/nchstp/od/latex.htm> accessed 27th February 2004.

⁸⁸ The Institute of Medicine, the federal body of experts responsible for advising the United States federal government on issues of medical care, research and education, found that the scientific literature, as well as experts that had studied the issue, showed that comprehensive sex and HIV/AIDS education programs and condom availability programs can be effective in reducing high-risk sexual behaviors while no such evidence supported abstinence-only programs. Cited in *Ignorance Only: HIV/AIDS, Human Rights And Federally Funded Abstinence-Only Programs In The United States*, Human Rights Watch, September 2002. <http://hrw.org/reports/2002/usa0902/>

⁸⁹ In 1996, the US Congress attached a provision to welfare legislation that established a federal program to fund programs teaching abstinence-until-marriage exclusively. Approximately \$100 million, including matching state funds, is spent annually on abstinence only education programs. <http://www.ncac.org/issues/abonlypresskit.html#background>

Among the factors driving this agenda is concern that comprehensive sexual health and HIV programmes for young people will hasten sexual debut or lead to promiscuity. However, an analysis of research regarding the impact of sexual health and HIV programming on the age of sexual debut of young people and levels of sexual activity do not bear out these concerns.⁹⁰ The so called ABC approach (Abstinence, Be faithful, Condoms) is being widely promoted as an effective comprehensive approach. However, while each aspect of ABC has a role to play in preventing the spread of HIV, it is not always clear that implementation of ABC is a comprehensive approach. For example, while the US Government has promoted ABC as a comprehensive approach, criticism of the *President's Emergency Plan for AIDS Relief* (PEPFAR) notes that the plan employs selective use of evidence to promote abstinence to the exclusion of other strategies, and re-stigmatizes condom use.⁹¹ The experience of Uganda has also been cited by proponents of abstinence only programmes as evidence to support the effectiveness of this approach. However, an analysis of national level survey data from Uganda concluded that among the range of interventions employed in that country – including abstinence, delays in sexual debut, reducing the number of sexual partners and increased condom use – increased abstinence by itself may have made the smallest contribution to lowering risk of HIV in Uganda. Furthermore, the reduction in the number of sexual partners and condom use both increased substantially more than did the proportion of young people abstaining from sex. Above all, it is important to note that Uganda's success can be attributable to a comprehensive programme, rather than abstinence only.⁹²

Programmes that emphasize abstinence and fidelity, while being effective for some people, at some stages of their life, do not address the range of experiences of people most at risk, and they do not provide the skills for the future sexual relationships of the great majority of people.⁹³ It is important to understand that fidelity requires the agreement of both people in a relationship. Many women, particularly those in high prevalence countries, do not have the power to control their partners' fidelity or to negotiate condoms within their relationships. Programmes need to equip all participants with the skills to manage the challenges that arise within abstinence, be faithful and condom use strategies, both for individual risk management, and to facilitate a supportive environment. Enabling participants to make informed decisions about their own risk, free of judgment, also empowers them to support others within their own families and networks to do so.

It is also vital that NGOs continue to advocate to build or maintain political and community support for a comprehensive range of interventions to address the risks of HIV transmission among people who inject drugs.⁹⁴ Injecting drug use is a major factor in epidemics in Asia, North America, Western Europe, in parts of Latin America, the Middle East and Northern

⁹⁰ *Dying to learn: Young people, HIV and the churches*, Christian Aid, October 2003, see Key Resources.

⁹¹ *Bush Global AIDS Plan: Long on Rhetoric, Short on Science and Solutions*, Center for Health and Gender Equity, Media release, 23rd February 2004, <http://www.genderhealth.org/globalAIDSstrategy.php> and *President's Emergency Plan for AIDS Relief* (PEPFAR): US Five Year Global HIV/AIDS Strategy, 2004, see chapter IV, <http://www.globalhealth.gov/>

⁹² Cohen, S. *Flexible But Comprehensive: Developing Country HIV Prevention Efforts Show Promise*, October 2002 <http://www.agi-usa.org/pubs/journals/gr050401.html> and *Beyond Slogans: Lessons From Uganda's Experience With ABC and HIV/AIDS*, December 2003 <http://www.guttmacher.org/pubs/journals/gr060501.html>, both articles in The Guttmacher Report on Public Policy.

⁹³ Good practice requires that those most at risk of HIV infection are given priority; see *Targeting vulnerability, promoting rights*, immediately below.

⁹⁴ Details of comprehensive programming to address IDU are outlined above.

Africa. In some Eastern European countries, especially the countries of the former Soviet Union, injecting drug use is driving an epidemic among young people.⁹⁵

It is abundantly clear that:

- needle and syringe programmes (NSPs) reduce the risk of transmission without contributing to an increase in drug use and
- that early implementation of NSPs has been a critical factor in avoiding a serious outbreaks of HIV among IDUs.⁹⁶

NGO HIV prevention programmes target, and involve, individuals and communities most vulnerable to HIV infection.

HIV prevention programmes need to:

- be informed by assessment of epidemiology and of social patterns of sexual activity and injecting drug use to identify the dynamics of HIV transmission
- target vulnerability by giving priority to populations at risk
- be informed by collection and review of feedback and other data about the difficulties that people encounter in relation to adopting safer practices, and the development of innovative activities to respond to these assessed unmet needs and
- involve communities at risk in participatory assessment, programme design, implementation and evaluation of prevention initiatives.

NGO HIV prevention programmes empower individuals to develop the skills to protect themselves from HIV infection.

Information on its own is insufficient to prevent HIV infection. HIV prevention involves people's private social, sexual and drug-using activities which are often controversial, hidden or stigmatised. Stigma and discrimination works to alienate people from access to information, education, and the means of prevention. The stigma associated with HIV infection itself and the stigmatization of risk related behaviours such injecting drug use, male to male sexual activity, sex work underscore the need for a rights-based approach to prevention.

Programmes and services need to offer intensive, interactive, personalised HIV prevention services targeted to those most at risk of HIV infection that address the real lives and situations of those most at risk of infection.⁹⁷

For example, those who already have or are likely to have multiple sexual partners, an appropriately focussed response is to provide support for use of condoms in their sexual encounters, whereas programmes advocating abstinence do not address their needs. A spectrum of harm minimisation for people who inject drugs is more effective at reducing HIV prevention and making treatment and care services accessible to people with HIV than a single emphasis upon preventing injecting drug use altogether. Targeting sexual health programmes, addressing STI prevention and treatment, including HIV prevention, for sex workers and their clients, and for men who have sex with men are appropriately focussed responses.

Prevention services and programmes targeted to people at risk of HIV infection need to provide:

⁹⁵ *Report on the Global HIV/AIDS Epidemic*, UNAIDS 20002, at page 94.

⁹⁶ *Global Mobilization of HIV Prevention: A Blueprint for Action*, page 15, see Key Resources.

⁹⁷ See information, education and communication above and Addressing vulnerability, Section 2.5.

- intensive, interactive, personalised HIV prevention services based individual assessment of their particular needs in relation to HIV prevention
- information, support and strategies to cope with situations where there are strong pressures to engage in unsafe activities
- opportunities for discussion of problems and issues they may encounter in sexual and emotional relationships
- discussion of issues for those new to particular risk behaviours and
- information and assistance to access further information, prevention commodities, treatment, care and support.

NGO HIV prevention programmes address the needs of PLHA.

Prevention services and programmes for PLHA need to:

- provide opportunities to consider how to deal with pressures to continue to engage in unsafe activities
- address the real-life difficulties of sero-discordant relationships
- cover the risks of re-infection with different strains of virus, where relevant because of the availability of anti-retroviral therapies
- cover household hygiene and infection precautions
- be realistic about continuing desire for sexual activities and emotional relationships and
- address issues regarding disclosure to sexual partners.

NGO HIV prevention programmes build social capital of individuals and communities vulnerable to HIV infection.

Community education and social marketing⁹⁸ programmes can enhance community knowledge about HIV prevention by maximising communities understanding of:

- the consequences of HIV infection
- the modes of transmission, informed by an understanding of and strategies to address myths about transmission
- risk reduction and risk elimination techniques, including how to access and use prevention commodities and
- how to access to VCT, treatment, care and support services.⁹⁹

However, community awareness raising initiatives alone are rarely cost effective in addresses the complexities of HIV prevention and the social and cultural norms that influence the capacity of individuals to make informed decisions to reduce their risk and sustain behaviour change.¹⁰⁰

Community programmes in prevention, treatment, care, support and advocacy can facilitate community mobilisation by:

- valuing and harnessing the expertise of PLHA and communities affected in participatory assessment, programme design, delivery, and evaluation
- encouraging and supporting the role of community leaders in the HIV response

⁹⁸ Social marketing is the marketing of public health goods or ideas through traditional marketing channels. See discussion of social marketing of condoms in *Cost Guidelines for HIV/AIDS prevention Strategies*, 2000, UNAIDS, http://www.unaids.org/html/pub/publications/irc-pub05/jc412-costguidel_en_pdf.htm

⁹⁹ Good practice principles in community education also need to address stigma and discrimination, see Section 4.3.

¹⁰⁰ *Beyond Awareness Raising: Community Lessons about Improving Responses to HIV/AIDS*, International HIV/AIDS Alliance, July 1998. <http://www.aidsalliance.org/eng/>

- integrating practical strategies within these programming to reduce the social isolation and stigmatization of PLHA and affected communities.

NGO HIV prevention programmes are evaluated for effectiveness.

See: Chapter 3 Operational Principles, Section 3.3 Programming planning which includes programme monitoring and evaluation.

NGOs advocate for a supportive legal and policy environment to support effective programming and promote human rights.

NGO advocacy programmes need to actively involve PLHA, affected communities, community leaders in promoting an enabling environment for HIV prevention by advocating for:¹⁰¹

- reform of legislation, such as public health and criminal laws, where they impede effective prevention efforts¹⁰²
- reform of laws and policy that stigmatize vulnerable groups such as sex workers, injecting drug users, and MSM, and/or undermine access to information, education and the means of prevention
- reform of laws relating to regulation of HIV related goods to ensure widespread availability of prevention commodities
- active political and community leadership on the value and effectiveness of harm reduction approaches to sharing injecting equipment
- health systems reforms to promote application of universal infection control, securing a safe blood supply, expansion of VCT services and access to HIV, STI and drug treatment programmes
- the development of health service infrastructure to support the prevention and care continuum and
- for wider availability of the female condoms¹⁰³
- for HIV vaccines and microbicide development including access to community preparedness measures.¹⁰⁴

NGOs advocate for adequate and appropriate research data to support an evidence-based approach to HIV/AIDS programming.

NGOs need to advocate for the availability of adequate and appropriate data to support an evidence-based approach to programming by:

- identifying when available epidemiological data is inadequate
- advocating for improvements to the type of data collected and/or the systems for collection and reporting
- identifying where social/ behavioural research is needed in order to better understand the risks associated with for HIV infection, the needs of PLHA and affected communities, and

¹⁰¹ See Chapter 2 key resources, particularly the *HIV/AIDS and Human Rights International Guidelines, including revised guideline 6*.

¹⁰² See *Criminal law, public health and HIV transmission: a policy options paper*. UNAIDS, June 2002, search by title, <http://www.unaids.org/en/default.asp>

¹⁰³ The female condom has been proven effective in reducing the risks of transmission and surveys indicate that the product would be used more widely by many sexually active women were it more widely available. *Global Mobilization of HIV Prevention: A Blueprint for Action* at page 14.

¹⁰⁴ See *HIV/AIDS and Human rights International Guidelines*, and ICASO's *Advocate's Guide International Guidelines on HIV/AIDS and Human Rights* (See Chapter 2 Key resources) which provides guidance on advocating for law and policy reform, education and national policy to support effective HIV prevention and reduce stigma and discrimination against PLHA and affected communities.

the social, political, cultural and economics factors that influence HIV transmission rates and the impacts of HIV/AIDS in a given context ¹⁰⁵

- advocating for necessary research to improve the appropriateness and effectiveness of programme interventions, including efforts to scale up programmes, and enhance advocacy efforts to promote an enabling environment that supports effective responses to HIV/AIDS
- building effective partnerships with research organizations and academic institutions to ensure research initiatives contribute to improving the evidence base that informs practice and
- engaging in joint research initiatives with social researchers.

NGOs develop and maintain the necessary organisational capacity to support effective HIV prevention.

Staff and volunteers need to be supported to:

- examine their own attitudes and beliefs and the impact these have on their ability to provide non-judgmental, inclusive processes and programmes
- understand and apply the organizational policies that ensure the rights of PLHA and affected communities and promote participation in services and programmes
- understand the realities of HIV transmission and prevention, the differing prevention needs of different vulnerable groups, based on local and regional epidemiology and local and international evidence about the effectiveness and efficiency of different interventions ¹⁰⁶
- develop the necessary knowledge and skills to support people to understand their risk and make informed decisions about protecting themselves against HIV infection
- continually improve programming and work practices by involvement in programme planning, monitoring and evaluation.

Key resources

The resources listed here provide:

- the evidence base for key interventions that underpin the good practice principles in prevention and can be used in advocating their application to governments, policy makers, donors and programmers and
- resources to support application of the good practice principles in design, implementation and evaluation of HIV prevention programmes.

Global Mobilization of HIV Prevention: A Blueprint for Action, Global HIV Prevention Working Group, July 2002. <http://www.kff.org/hivaids/200207-index.cfm>

Access to HIV Prevention: Closing the Gap, Global HIV Prevention Working Group, May 2003. <http://www.kff.org/hivaids/200305-index.cfm>

WHO *Evidence for Action* includes papers on: Methods of assessing and monitoring HIV risk among IDUs, and effectiveness of HIV information, education and communication for IDU; community based HIV interventions; needle and syringe programs; drug dependence treatment; prevention and care interventions for young and new IDU and structural factors in HIV prevention among IDU. (*xx currently in draft, final reference & website link to be added later*).

¹⁰⁵ For example, research such as the Population Council's study to identify sociocultural and structural issues likely to be potential barriers to or facilitating factors for the introduction of microbicides. <http://www.popcouncil.org/hivaids/index.html>

¹⁰⁶ See also Section 3.2 Organizational management.

Spreading the light of science: Guidelines on harm reduction related to injecting drug use, International Federation of Red Cross and Red Crescent Societies, December 2003.
http://www.ifrc.org/what/health/tools/harm_reduction.asp

What religious leaders can do about HIV/AIDS: Action for Young Children and Young People, UNICEF, World Council for Religions for Peace and UNAIDS, November 2003,
http://www.unicef.org/publications/index_19024.html

UNAIDS resources below: Search by title, <http://www.unaids.org/en/default.asp>

- *Partners in Prevention: International cases studies of effective health promotion practices in HIV/AIDS*, 1998
- *Sex work and HIV/AIDS*, June 2002
- *Gender and AIDS: Best practices/ programmes that work*, August 2002
- *Prevention of HIV from Mother to Child: Strategic Options*, 1999

International HIV/AIDS Alliance at <http://www.aidsalliance.org/eng/>

- *An Introduction to Promoting Sexual Health for Men Who Have Sex with Men and Gay Men – A Training Manual*, November 2001
- *Developing HIV/AIDS work with Drug Users – A Guide to Participatory Assessment and Response*, August 2003
- *Positive Prevention: Prevention Strategies for People with HIV/AIDS*, July 2003
- *Beyond Awareness Raising: Community Lessons about Improving Responses to HIV/AIDS*, July 1998.

Family Health International (FHI) has produced a series of strategic frameworks:

- Behaviour change communication
- Reducing Mother-to-child transmission
- Sexual transmitted infection

<http://www.fhi.org/en/HIVAIDS/Publications/Strategies/index.htm>

Unintended consequences: Drug policies fuel HIV epidemic in Russia and Ukraine, Open Society Institute, International Harm Reduction Development, 2003.

http://www.soros.org/initiatives/ihrd/articles_publications/publications/unintendedconsequences_20030414

Dying to learn: Young people, HIV and the churches, Christian Aid, October 2003.

<http://www.christian-aid.org.uk/indepth/310learn/index.htm>

FHI fact sheets offers on many aspect of HIV prevention, including mobile populations, MSM, MTCT, IDU <http://www.fhi.org/en/HIVAIDS/FactSheets/index.htm>

Meeting the Behavioural Data Collection Needs of National HIV/AIDS and STD Programmes, IMPACT, FHI and UNAIDS, May 1998,

<http://www.fhi.org/en/HIVAIDS/Publications/manualsguidebooks/datacollection/index.htm>

See also key resources in Chapter 2, for advocacy resources.

4.2 Treatment, care and support

Overview

PLHA and affected communities' access to treatment, care and support varies enormously, with vast number of PLHA unable to access basic care and support services. Health systems in the worst affected countries are often ill equipped to meet basic health needs of communities, let alone to provide a comprehensive range of treatment¹⁰⁷, care and support services for PLHA, partners, family members and carers.¹⁰⁸ The compelling urgency to respond to the needs of partners, family and community members living with HIV/AIDS who are sick and/or dying has meant communities have been central to the provision of care and support. NGOs been vital to supporting community responses and expanding community involvement since the world first became aware of HIV/AIDS.

ARV therapy became widely available in many industrialized countries in the mid 1990's, reducing morbidity and mortality and improved quality of life for the many PLHA who have access to it. Yet, despite the benefits of ARVs, millions of people in developing countries continue to die each year. As discussed in Chapter 1, there is global commitment to address this profound inequity, born at least in part by the strenuous efforts of many NGOs and communities in pressing the urgency of ARV access in developing countries. There is also recognition that NGOs, PLHA and affected communities have significant expertise that can be built upon for the rapid expansion of ARV therapy.¹⁰⁹

The good practice principles outlined in this section can be more readily applied where health infrastructure is adequate to support comprehensive and integrated treatment, care and support services and programmes. In contexts where health infrastructure is weak and resources are limited, these principles are aspirational. That is, NGOs need to continue to advocate for programmes and services that are consistent with the principles outlined in this Code. In doing so, NGOs advocacy efforts need to be informed by and responsive to needs of PLHA and affected communities and their experiences in accessing services and programmes. Stigma and discrimination remains significant obstacles to testing, and access to treatment, care and support. Advocacy efforts to improve the range, accessibility and quality of treatment, care and support must be linked to strategies for eliminating stigma and discrimination, so that PLHA and communities affected are confident to provide and access services and programmes, in the knowledge that their rights will be respected.¹¹⁰

¹⁰⁷ 'Treatment' includes treatment of opportunistic infections as well as ARVs.

¹⁰⁸ The wide ranging impacts of HIV/AIDS on PLHA, their partner, families, and carers is considered in Section 4.4 Impact Mitigation. In this section 'affected communities' refers to the care and support needs of the partners, families, including children and carers of PLHA.

¹⁰⁹ *Mobilizing communities to achieve 3 x 5*, WHO, December 2003, <http://www.who.int/3by5/publications/briefs/communities/en/> and *Emergency scale up of ARV therapy in resource limited settings: Technical and operational recommendations to achieve 3 x 5*, Chapter 1, WHO, December 2003, http://www.who.int/3by5/publications/documents/en/zambia_doc_final.pdf

¹¹⁰ See Chapter 2, Section 3.5 Access and Equity and Section 4.3 Addressing Stigma and Discrimination.

Good Practice Principles

Voluntary HIV counselling and testing services are accessible, and confidential.

In many parts of the world severely affected by HIV/AIDS, as few as one in ten people with HIV know that they are infected.¹¹¹ Access to treatment is likely to provide a new incentive for people to know about their HIV status, bringing with both improvements to the health of many PLHA and opportunities to strengthen prevention efforts. It is estimated that by 2005 there will be up to 180 million people in need of VCT services annually.¹¹² There is an urgent need for VCT services on a much larger scale than has occurred to date, including implementing VCT within different types of health settings in order to maximise entry points to HIV prevention and HIV treatment, care and support.¹¹³

In scaling up VCT services, NGO need to ensure or advocate that others providers ensure a rights based and comprehensive approach to all VCT services. VCT services should:

- be voluntary, enabling people to give their informed consent to be tested, based on pre-test information about the purpose of testing and the treatment and support available once the result is known
- post-test support and services advise those who test HIV positive on the meaning of their diagnosis, referral to the treatment, care and support and prevention programmes and services available to assist them. For those who test negative, post-test counselling or discussions offer an important opportunity to reflect on personal risk reduction strategies or to refer people to prevention programmes and
- ensure confidentiality of information about a persons' HIV status, and confidentiality of medical records and test results.

NGOs treatment, care and support programmes are integrated into a comprehensive network of health and care services.

The need to ensure programmes and services are integrated within the prevention - care continuum, supported by a rights based approach, has been examined in Section 4.1 HIV prevention.

NGOs need to provide and/or advocate for a comprehensive and integrated range of treatment, care and support services and programmes.¹¹⁴ ¹¹⁵ A comprehensive range of treatment, care and support services and programmes for PLHA need to encompass:

- accessible and high quality VCT services¹¹⁶
- tailored health information, including information about ARV treatment, including side effects and adherence issues, available care and support services, related health issues including TB and STIs and HIV prevention services¹¹⁷

¹¹¹ *The Right to Know – New Approaches to HIV Testing and Counselling*, WHO, 2003 (see Key resources)

¹¹² *The Right to Know – New Approaches to HIV Testing and Counselling*, WHO, 2003 (see Key resources)

¹¹³ See for example: *Integrating HIV voluntary counselling and testing into reproductive health settings: (See key resources) Stepwise guidelines for programme planners, managers and service providers*, IPPF and UNFPA, February 2004, xx add web ref when guidelines finalized.

¹¹⁴ Generally, NGOs provide only some components of a comprehensive treatment, care and support services and programmes, often including home based care, support programmes and the like, although there are NGOs that provide a wider range including clinical services.

¹¹⁵ *HIV Care & Support: A Strategic Framework*, FHI, June 2001 provides a useful analysis of the components of a comprehensive approach to treatment, care and support, see Key Resources.

¹¹⁶ See Good practice principles above regarding VCT services.

- tailored support programmes, including counselling, discussion groups, peer support, spiritual support
- care services including home based care, nursing care, palliative care
- HIV treatment programmes, including clinical management of opportunistic infection, HIV related illness, monitoring and management of disease progression and access to ARV therapy¹¹⁸
- treatment and prevention of TB and STIs¹¹⁹
- support and assistance in relation to non-clinical aspects of treatment, including peer support, adherence and nutritional needs
- a range of impact mitigation programmes including material including food, clothing, and legal assistance, socioeconomic support and
- support, respite and training for family members and carers.¹²⁰

No single service can meet all the needs of PLHA and their families and carers. To ensure a patient-centred approach, NGO treatment, care and support services need to be integrated within a network of services. In order to facilitate optimum access to the full range of available services and programmes NGOs need to:

- know about allied services
- form good partnership arrangements with allied services and
- establish effective referral mechanisms.

NGOs treatment, care and support programmes target, and involve, individuals and communities most affected by HIV/AIDS.

NGO treatment, care and support services and programmes need to:

- work with communities to identify treatment, care and support needs
- involve PLHA, their family, partners, dependents and carers participatory assessment, programme design, implementation and evaluation
- are informed by collection and review of feedback and other data, including anecdotal evidence, about the specific needs of communities, and the development of innovative activities to respond to these assessed unmet needs and
- ensure services and programmes are directed to those in need, paying particular attention to the ways that gender, age and stigmatization of particular communities such as sex workers IDU and MSM affects access.¹²¹

PLHA are not merely recipients of treatment, care and support services. They are also providers, educators, managers, planners, evaluators and advocates. The benefits of involving PLHA, their carers and communities in health care are many including ensuring that services are relevant, credible and appropriate and harnessing their knowledge about treatments and services with their unique, first-hand experiences. Involvement of PLHA and their carers and communities must not expose people to stigma and breaches of confidentiality or create

¹¹⁷ Also see Good practice principles about enabling PLHA to make informed decisions about meeting their treatment, care and support needs below.

¹¹⁸ Also see Good practice principles regarding advocating for access to treatment, including ARVs below.

¹¹⁹ Approximately one-third of PLHA worldwide are co-infected with *M. tuberculosis*, and 70% of them live in sub-Saharan Africa. Tuberculosis is also the leading cause of death among HIV-infected people, and HIV has been responsible for a global surge in number of cases of active tuberculosis. *Report on the Global HIV/AIDS Epidemic*, UNAIDS, 2000, page 151.

¹²⁰ See also Good practice principles below regarding Section 4.3 Addressing Stigma and Discrimination and Section 4.4 Impact Mitigation.

¹²¹ Also see Section 3.5 Access and Equity.

dependency. Active engagement of PLHA and affected communities is critical in preparing communities for ARV treatment access. Such involvement ensures that treatment services providers understand community beliefs, knowledge and needs. Communities are important brokers in the process of building ARV treatment literacy and HIV health literacy more generally.¹²²

NGOs enable PLHA and affected communities to meet their treatment, care and support needs.

When providing treatment, care and support services for PLHA, NGOs need to:

- ensure individual assessment of people's treatment, care and support needs
- take a holistic approach that ensures that the social, economic and psychosocial impacts of HIV/AIDS on PLHAs, their partners, children, other family members and carers are addressed¹²³
- provide tailored support programmes, including social, spiritual, psychological, and support to enable people to deal with the non-clinical impacts of HIV and make informed decisions about their treatment, care and support needs
- provide information in a manner that 'speaks to' people from a variety of contexts, with varying levels of literacy and familiarity with HIV and
- enhance the capacity of PLHA and affected communities to access programmes and services to meet their needs.

An essential part of the response to HIV/AIDS has been and will continue to be home and community based care. NGOs care and support programmes need to support partners, other families members, friends, volunteers providing care and support for PLHA by:

- providing training and resources to ensure carers have appropriate information about HIV/AIDS prevention and care and knowledge of available health services
- supporting carers to develop and maintain the necessary skills to provide quality care and
- ensuring carers are supported to avoid burnout through counselling, peer and social support and respite.

NGOs treatment, care and support services are equitable, accessible.

PLHA are entitled to treatment, care and support services that take into account their unique and individual needs. NGO services and programmes need to be responsive and appropriate to individuals. Ensuring that services are not only available but also appropriate is particularly important for groups that have unique needs as a result of being marginalised because of their gender, behaviour, profession, sexuality or status. Ensuring access to services are equitable means taking into consideration socio-economic status, geographical location, age, gender, severity and duration of infection and vulnerability when a PLHA seeks a service.¹²⁴

NGOs advocate for access to medicines and enabling environment for effective treatment, care and support services for PLHA and affected communities.

NGOs need to advocate for:

¹²² *Improving Access to HIV-related Treatment*, International HIV/AIDS Alliance, *Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa*, WHO, see Key resources below.

¹²³ Also see Section 4.4 Impact Mitigation.

¹²⁴ Also see Section 3.5 Access and Equity.

- access to medicine including ARVs and treatment for opportunistic infections¹²⁵ including improved supply of free drugs from governments, and on international issues regarding compulsory licensing and parallel importing and low international prices for HIV/AIDS related drugs¹²⁶
- laws relating to regulation of HIV related goods to ensure widespread availability of safe and effective medication at affordable prices¹²⁷ and
- involvement of PLHA and affected communities in design, implementation and evaluation of treatment, care and support programmes.

Also see good practice principle regarding advocacy in the Section 4.1 HIV Prevention.

NGOs develop and maintain organisational capacity to enable effective treatment, care and support programmes.

Staff and volunteers need to be supported to:

- understand the complexities of the treatment, care and support needs of PLHA and their families and carers the impacts of HIV/AIDS on PLHA
- the different needs of particular groups in their communities
- develop the necessary knowledge and skills to design, deliver and evaluate programmes and
- develop the necessary knowledge and skills to support people to make informed decisions about their treatment, care and support needs.

Also see good practice principles in developing and maintaining organisational capacity to support effective programming generally outlined in section 4.1 HIV prevention, at page 34.

NGOs advocate for adequate and appropriate research data to support an evidence-based approach to programming.

See good practice principles in advocating for adequate and appropriate research data to support an evidence-based approach to programming in section 4.1 HIV prevention, at page 33.

NGOs treatment, care and support services are monitored and evaluated for effectiveness.

See Chapter 3 Operational Principles, Section 3.3 Programming planning which includes programme monitoring and evaluation.

Key resources

The Right to Know – New Approaches to HIV Testing and Counselling, World Health Organisation, 2003

<http://www.emro.who.int/asd/backgrounddocuments/egy0703/RighttoKnow.pdf>

¹²⁵ See discussion of international resolutions and key resources in Chapter 2 that can be used to support treatment advocacy efforts in Chapter 2.

¹²⁶ See range of resources produced by Medecins Sans Frontieres, Access to Essential Medicines Campaign <http://www.accessmed-msf.org/prod/view.asp?catid=1&>

¹²⁷

Scaling up HIV Testing and Counselling Services – A toolkit for programme managers
International HIV/AIDS Alliance, xx Currently in draft: December 2003,
<http://www.aidsalliance.org/eng/>

Integrating HIV voluntary counselling and testing into reproductive health settings: Stepwise guidelines for programme planners, managers and service providers, IPPF and UNFPA, February 2004, xx add web ref when guidelines finalized.

HIV Care and Support: A Strategic Framework, FHI, June 2001, search by title
<http://www.fhi.org/en/HIVAIDS/Publications>

Care, Involvement and Action: Mobilising and supporting community responses to HIV/AIDS care and support in developing countries, International HIV/AIDS Alliance, July 2000,
<http://www.aidsalliance.org/res/reports/Care%20Report.pdf>

Community home-based care for people living with HIV/AIDS, International Federation of Red Cross and Red Crescent Societies, 2003,
http://www.ifrc.org/cgi/pdf_pubs.pl?health/hivaids/hbc.pdf

HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS, FHI, 2003, search by title <http://www.fhi.org/en/HIVAIDS/Publications>

Improving Access to HIV/AIDS-Related Treatment – A report sharing experiences and lessons learned on improving access to HIV/AIDS-related treatment, International HIV/AIDS Alliance, June 2002, http://www.aidsalliance.org/res/reports/Access_To_Treatment_Report.pdf

Improving access to care in developing countries, UNAIDS, CD ROM and *Handbook on access to HIV/AIDS related treatments: A collection of information, tools and resources for NGOs, CBOs and PLWHA groups*, UNAIDS, WHO and International HIV/AIDS Alliance, May 2003. Search by title, <http://www.unaids.org/en/default.asp>

A Public Health Approach to Antiretroviral Treatment: Overcoming Constraints, WHO, 2003,
http://www.who.int/hiv/pub/prev_care/en/PublicHealthApproach_E.pdf

Saving Mothers, Saving Families: the MTCT- Plus Initiative, WHO 2003,
http://www.who.int/hiv/pub/prev_care/pub40/en/

Antiretroviral Therapy in Primary Health Care: Experience of the Khayelitsha Programme in South Africa, WHO, 2003 http://www.who.int/hiv/pub/prev_care/en/South_Africa_E.pdf

Gender, AIDS and ARV Therapy: Ensuring that Women Gain Equitable Access to Drugs within US Funded Treatment Initiatives, Centre for Health and Gender Equity, February 2004
<http://www.genderhealth.org/pubs/TreatmentAccessFeb2004.pdf>

HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS, FHI, <http://www.fhi.org/en/HIVAIDS/Publications>

What religious leaders can do about HIV/AIDS: Action for Young Children and Young People, UNICEF, World Council for Religions for Peace and UNAIDS, November 2003,
http://www.unicef.org/publications/index_19024.html Chapter 6.

4.3 Addressing stigma and discrimination

Overview

Stigma is a process of producing and reproducing inequitable power relations, where negative attitudes towards a group of people, on the basis of particular attributes such as their HIV status, gender, sexuality or behaviour for example, are created and sustained to legitimize dominant groups in society. Discrimination is a manifestation of stigma. **Discrimination** is any form of arbitrary distinction, exclusion or restriction, whether by action or omission, based on a stigmatised attribute.

It is well recognised that stigma and discrimination are significant barriers to preventing the spread of HIV and alleviating its impacts and takes many different forms.¹²⁸ Laws and policy often stigmatize PLHA and affected communities. For example, in many countries, homosexual sex and sex work remain illegal and punishable by imprisonment. Discrimination occurs in a wide variety of settings including health care services, schools and workplaces, and takes many forms including:

- rejection and social isolation
- harassment
- unfairly treatment, neglect or failure to provide services
- or refusal of, services
- loss of employment or housing
- breaches of confidentiality.¹²⁹

HIV related stigma and discrimination emerges from and reinforces pre-existing gender, race and socio-economic inequities and prejudices about injecting drug use, sex work and homosexuality. Pre-existing prejudices and inequities, combined with fears about HIV infection, provide a fertile environment for HIV related stigma and discrimination to flourish. A significant body of research demonstrates that HIV related stigma and discrimination is widespread: police harassment of sex workers, injecting drug users and men who have sex with men; PLHA's refused access to health care; breaches of confidentiality; discrimination in employment and sexual abuse and violence against women and girls.¹³⁰ Families, partners, children of PLHA also bear the brunt of stigma and discrimination.¹³¹

Stigma and discrimination compound vulnerability, and have damaging health, financial, social and emotional consequences for PLHA and affected communities. The effect of

¹²⁸ The rationale for a right-based approach, that addresses the stigmatization of and discrimination against PLHA and affected communities, is examined in the discussion of the human rights principles which underpin the Code and the need to address vulnerability. (see Chapter 2).

¹²⁹ *HIV and AIDS - related stigmatization, discrimination and denial: forms, contexts and determinants*, UNAIDS and *HIV Related Stigma and Discrimination: A Conceptual Framework and an Agenda for action*, see Key resources below.

¹³⁰ See documents in footnote 95; *Asia Pacific Network of People Living with HIV/AIDS: Documentation of AIDS-Related Discrimination in Asia*, APN+, See Key Resources below; and also see Human Rights Watch reports, for example: *Policy Paralysis: A Call for Action on HIV/AIDS-Related Human Rights Abuses Against Women and Girls in Africa*, December 2003; *Locked Doors: The Human Rights of People Living with HIV/AIDS in China*, August 2003; *Ravaging the Vulnerable: Abuses Against Persons at High Risk of HIV Infection in Bangladesh*, August 2003; *Just Die Quietly: Domestic Violence and Women's Vulnerability to HIV in Uganda*, August 2003; *Abusing The User Police Misconduct, Harm Reduction And HIV/AIDS In Vancouver*, May 2003 http://hrw.org/doc/?t=hivaid_s_news

¹³¹ See for example, *The role of stigma and discrimination in increasing vulnerability of children and youth infected with and affected with HIV/AIDS*, Save the Children UK, 2001, http://www.savethechildren.org.uk/temp/scuk/cache/cmsattach/1104_stigma.pdf

stigmatization of and discrimination is to alienate those most affected by HIV/AIDS, making people fearful of becoming aware of their status, adopting preventive measures and accessing counselling, testing, treatment, care and support.¹³² Fear of and experience of stigma and discrimination can be internalized, resulting in self isolation, undermining people's self esteem and their capacity to sustain safer behaviours and motivation to exercise control over own health.¹³³

Addressing stigma and discrimination requires a multifaceted approach that ensures:

- individuals know about their rights, and supported to respond to stigma, discrimination and their consequences.
- communities are supported to examine the nature and impact of stigma and discrimination and play an active role in eliminating stigma and discrimination
- institutions, such as workplaces and health care settings are supported to promote non-discrimination through effective workplace policies and programmes and
- advocacy efforts promote an enabling environment by reform of laws and policy that stigmatize PLHA and affected communities.

Good Practice Principles

NGO anti-discrimination programmes provide individuals and communities with information about their rights and support to respond to discrimination.

Individuals and communities must be able to name their experience as one of discrimination, understand their rights and have sufficient information and resources in order to take action in response to discrimination they experience.

Anti-discrimination programmes need to provide PLHA and affected communities with:

- easily accessible information about their rights
- advice about and support to take action to respond to discrimination, through individual advocacy services or effective referral to agencies that can provide individual advocacy services such as human rights organizations, legal services and unions and
- support to respond to, and address the consequences of, discrimination including peer support, counselling, discussion groups, effective referral to housing, employment and related services.

NGOs monitor and document individual and community experiences of stigma and discrimination.

Monitoring HIV related stigma and discrimination, raising awareness about their impact and utilizing this knowledge to inform education and advocacy efforts is essential to combating the epidemic.

It is important that programmes incorporate a systematic approach to documenting and analysing people's experiences of stigma and discrimination and efforts to respond to discrimination in order to understand:

- the nature of stigma and discrimination within a given context and

¹³² The impacts of discrimination upon vulnerable groups and the consequences for effective responses to HIV/AIDS are examined in Human Rights Watch reports above and research outlined in *HIV Related Stigma and Discrimination: A Conceptual Framework and an Agenda for action* (See key resources).

¹³³ Research shows that stigmatization is often internalized, manifesting in shame and self isolation. *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia* (See key resources).

- individuals and communities experiences of using anti-discrimination complaint mechanisms, other legislatively-based complaint mechanisms and informal strategies for addressing discrimination.

NGO anti-discrimination programmes respond to systemic discrimination.

Relevant research and data derived from monitoring PLHA and affected communities' experiences of stigma and discrimination can be used to:

- identify systemic discrimination in particular settings such as health care, employment, prisons
- identify specific institutions that promote stigmatization of PLHA and affected communities such as within the police and military services and the media
- prioritize and inform targeted advocacy and education initiatives in setting where discrimination is common.

For example, where widespread discrimination in health care settings is occurring, priority could be given to advocating for the development and implementation of HIV policies and practices that prevent discrimination including effective procedures to ensure:

- confidentiality is protected
- testing is voluntary and supported by pre and post test counselling
- informed consent to testing and treatment
- application of universal infection control and
- staff training to support implementation of anti discrimination policies in practice and
- availability and accessibly of complaint mechanisms, to address discrimination when it occurs.

NGO anti-stigma programmes address community prejudices.

Programmes need to address stigmatization of PLHA and affected communities by:¹³⁴

- involving PLHA and affected communities in the design, delivery and evaluation
- involving political, religious and community leaders in challenging HIV related stigma and discrimination¹³⁵
- enhancing community knowledge about the forms, causes and effect of HIV related stigma and discrimination
- creating opportunities for communities to examine their prejudices and address fears and misconceptions about transmission of HIV and
- utilizing a range of strategies including public awareness campaigns, participatory workshop activities, and active involvement by communities in delivery of prevention and care programmes.

NGOs advocate for laws and public policy that address the stigmatisation of and discrimination against PLHA and affected communities.

Relevant research, data derived from monitoring PLHA and affected communities' experiences of stigma and discrimination and governments' international human rights obligations can be used to:

- inform advocacy efforts to reform laws and policies that stigmatize PLHA and affected communities

¹³⁴ See *Understanding and Challenging HIV Stigma: Toolkit For Action* in Key Resources.

¹³⁵ For example, *What religious leaders can do about HIV/AIDS: Action for Young Children and Young People*, see Key Resources below.

- advocate to enact or improve anti-discrimination and other protective laws and policies, including privacy and informed consent to testing and treatment
- advocate for establishing or improving legal and related support to enable PLHA and affected communities to respond to discrimination
- identify barriers to using available legislative and non-legislative complaints systems and remedies and
- promote complaint systems that are appropriate for and accessible to PLHA and affected communities.¹³⁶

Advocacy programmes need to be:

- developed and implemented by actively involving PLHA, affected communities, community leaders¹³⁷
- informed by or developed in partnership with organizations working to promote and protect human rights, including women's rights, the rights of children, among others.

NGOs foster partnerships with human rights NGOs, legal services and unions.

Programmes designed to address stigma and discrimination need to be supported by fostering partnerships with human rights organizations and institutions, legal services, lawyers, unions, related advocacy agencies in order to:

- develop awareness of HIV-related discrimination and encourage development of HIV related legal and advocacy expertise
- ensure access to legal advice and advocacy for individuals seeking to enforce their rights
- ensure access to organizations and individuals that can assist in training staff and volunteers about HIV related legal issues and referral networks and
- develop joint advocacy strategies and programmes to address HIV related discrimination and stigma and promote the protection of human rights more broadly, including promoting the rights of women and children and addressing the underlying causing of vulnerability such as poverty, and inequities in access to education.

NGOs advocate for adequate and appropriate research data to support an evidence-based approach to programming.

See good practice principles in advocating for adequate and appropriate research data to support an evidence-based approach to programming in section 4.1 HIV prevention, at page 33.

NGOs monitor and evaluate their anti-stigma and discrimination programmes for effectiveness.

See Chapter 3 Operational Principles, Section 3.3 Programming planning which includes programme monitoring and evaluation.

NGOs develop organisational capacity to address stigma and discrimination.

Staff and volunteers need to be supported to:

¹³⁶ See *HIV/AIDS and Human rights International Guidelines*, and ICASO's *Advocate's Guide International Guidelines on HIV/AIDS and Human Rights* (See Chapter 2 Key resources) which provides guidance on advocating for law and policy reform to address stigma and discrimination against PLHA and affected communities.

¹³⁷ See for example, The BOND Guidance Notes series including guidance notes on participatory advocacy, <http://www.bond.org.uk/pubs/index.html#uk>

- examine their own attitudes and beliefs and the impact these have on their ability to provide non-judgmental, inclusive processes and programmes
- understand and apply the organizational policies that ensure the rights of PLHA and affected communities and promote participation in services and programmes
- understand the nature of HIV related stigma and discrimination, the rights of PLHA and affected communities
- develop the necessary knowledge and skills to support people to take action in response to discrimination and/or to make appropriate referrals.

Key resources

HIV and AIDS - related stigmatization, discrimination and denial: forms, contexts and determinants, UNAIDS, June 2000, search by title
<http://www.unaids.org/EN/other/functionalities/Search.asp>

HIV Related Stigma and Discrimination: A Conceptual Framework and an Agenda for action, Horizons Program, May 2002. <http://www.popcouncil.org/pdfs/horizons/sdcncptlfrmwrk.pdf>

Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia, International Centre for Research on Women (ICRW), 2003. <http://www.icrw.org/docs/stigmareport093003.pdf>

Understanding and Challenging HIV Stigma: Toolkit For Action, Change and ICRW, September 2003, <http://www.changeproject.org/technical/hivaids/stigma.html>

Protocol for identification of discrimination against people living with HIV/AIDS, UNAIDS, 2000 and *Handbook for legislators on HIV/AIDS, human rights and the law – Executive Summary*, UNAIDS 1999, search by title, <http://www.unaids.org/EN/>

Asia Pacific Network of People Living with HIV/AIDS: Documentation of AIDS-Related Discrimination in Asia, December 2003. (xx unpublished, add APN+ web page reference when available)

Signs of Hope, Steps for change, Ecumenical Advocacy Alliance, 2003. <http://www.e-alliance.ch/hivaids.jsp> CD Rom with more than 100 multi-lingual resources, with a particular focus on mobilizing and enhancing the role of faith communities and religious leaders in addressing HIV/AIDS related stigma and discrimination.

What religious leaders can do about HIV/AIDS: Action for Young Children and Young People, UNICEF, World Council for Religions for Peace and UNAIDS, November 2003, http://www.unicef.org/publications/index_19024.html

The ILO Code of Practice on HIV/AIDS and the world of work, 2001 and *Implementing the ILO Code of Practice on HIV/AIDS and the world of work: an education and training manual*, 2002, International Labour Organization.
<http://www.ilo.org/public/english/protection/trav/aids/code/codemain.htm>

See also key resources in Chapter 2 for advocacy resources.

4.4 Impact mitigation

Overview

HIV/AIDS has devastating and far reaching implications for individuals, families, communities, and societies. Epidemic diseases are not new but what sets HIV/AIDS apart is its unprecedented negative impact on the social and economic development of nations, particularly in high prevalence regions. Skilled personnel in public, social, education and health care services are becoming ill and dying, undermining the capacity of services to meet demands that continue to escalate as a consequence of HIV/AIDS. The pandemic is reducing labour and agricultural productivity, exacerbating global poverty and vulnerability to HIV/AIDS infection. Millions of children in the developing countries are without adequate care and support, placing considerable strain and pressure on families and communities to care for orphans and children made vulnerable by HIV/AIDS (OVC). As parents and care givers become ill or die, children are increasingly shouldering the burden for generating an income, food production and taking care of ill family members.¹³⁸ Women and girls bear a large proportion of the burden of AIDS care, both in the formal care sector and informally in communities. This is particularly so in developing countries where the bulk of care happens in communities and families. This often leads to girls having to leave school, women having diminished opportunities for economic independence, and women living with HIV/AIDS struggling to meet their own as well as their families care needs, further entrenching gender inequities.¹³⁹

Why do we use the term 'orphans and children made vulnerable by HIV/AIDS' (OVC)?

Children are affected by HIV/AIDS in a myriad of ways, not only when parents die of AIDS. There are increasing numbers of children living with sick or dying parents. Children are often required to drop out of school to provide care or generate an income for the family. Many children affected by HIV/AIDS are at risk of exclusion, abuse, discrimination and stigma.

HIV/AIDS impacts on individuals in complex ways. The non clinical impacts of HIV/AIDS on PLHA are multifarious and often include:

- fear of and/or despair about the consequences of disease progression, effects of illness and possibility of death
- fear of infecting others
- social isolation, including deterioration of family relationships, reduction or loss of social status
- fear about the future wellbeing of their partner and children
- economic impact including reduction or loss of livelihood or employment, inability to support dependents and
- the many manifestations of stigma and discrimination.

The impacts of HIV/AIDS on family members, partners and dependents of PLHA include:

- relationship tensions and breakdown
- emotional consequences of, personal fears in advance of and effects of bereavement
- stigma and discrimination
- inadequate resources for food, child care, housing, education, health related expenses
- pressures associated with caring for PLHA and family members affected by HIV/AIDS

¹³⁸ *Children on the Brink 2002: A Joint Report on Orphans Estimates and Program Strategies*, See Impacts on children, families and communities pages 9 – 11. Also see *Africa's Orphaned Generation*. See Key Resources below.

¹³⁹ *Gender and HIV/AIDS: Overview report*, at page 24, see Chapter 2 Key resources.

- loss or reduction of family livelihood and
- pressures on children and young people to provide for or contribute to meeting the families economic and care needs
- children being deprived of consistent and responsive care and opportunities to learn skills that children learn in supportive family and community settings and
- children and widows being deprived of inheritance.

Good practice principles for programming to respond to the needs of PLHA and affected communities, including families of PLHA are outlined in Section 4.1 HIV Prevention, Section 4.2 Treatment Care and Support and Section 4.3 Address Stigma and Discrimination. Good practice principles for programming to respond to the needs of carers are outlined in Section 4.2 Treatment Care and Support. Accordingly, this section focuses on good practice principles in programming for OVC and addressing the wider socio-economic impact of HIV/AIDS on communities.

Good Practice Principles

NGO impact mitigation programmes target, and involve, individuals and communities most affected by the impact of HIV/AIDS

Impact mitigation programmes need to:

- work with communities to identify and define needs and identify vulnerable children and households
- involve PLHA, their family, partners, dependents and carers in participatory assessment, programme design, implementation and evaluation
- are informed by collection and review of feedback and other data, including anecdotal evidence, about the specific needs of communities, and the development of innovative activities to respond to these assessed unmet needs and
- target those most vulnerable to the impacts of HIV/AIDS, including vulnerable children, not only children orphaned by AIDS.

NGO impact mitigation programmes are integrated within and/or linked to HIV prevention, treatment, care and support and anti-stigma and discrimination programmes.

Measures to address the material and psychosocial needs of PLHA and their families, partners, dependents, carers and OVC need to be incorporated within treatment, care and support, anti-discrimination and HIV prevention programmes. For example, care and support programmes for PLHA take a holistic approach to needs assessment and appropriate service delivery and referral to programmes and services to address the social, economic and psychosocial impacts of HIV/AIDS on partners, family members, carers, and children of PLHA.

NGO impact mitigation programmes use a range of methods to meet the variety of needs of individuals and communities.

Direct services for individuals affected by HIV/AIDS need to include:

- peer support and counselling
- material and practical assistance, including food aid, clothing, schools fees, childcare
- assistance with household hygiene and sterilisation precautions
- support, training and resources for carers (xx add cross ref to TC&S section)
- comprehensive programming for OVC ¹⁴⁰

¹⁴⁰ See following Good practice principles regarding comprehensive programming for OVC.

- employment support (including both those wanting to stay in their jobs and also those wanting to find new employment)
- facilitation of new sources of livelihood, including micro-finance and micro-credit initiatives.¹⁴¹

Also see NGOs role in advocating for mainstreaming of HIV/AIDS within humanitarian and development work below.

NGO impact mitigation programmes for orphans and vulnerable children affected by HIV/AIDS are child centred, family and community focussed and rights based.

Impact mitigation programmes need to take a rights-based approach, guided by the principles enunciated in the *Convention on the Rights of the Child (CRC)*.¹⁴² The principles in the CRC include:

- the right to survival, wellbeing and development
- non-discrimination¹⁴³
- giving primacy to the best interests of the child in all actions regarding the child
- fostering participation of children including the right to express their views freely in all matters affecting them and the right to freedom of expression; freedom to seek, receive and impart information and ideas of all kinds
- protecting children from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse and
- protecting children from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral or social development.¹⁴⁴

Impact mitigation programmes for OVC need to:

- involve children and young people as active participants
- increase the capacity of children and young people to meet their own needs through access to quality education, protection from exploitation and developing the skills to care for themselves
- recognize that families and communities are the primary social safety net for OVC
- support parents living with HIV/AIDS to fulfill their parenting, including succession planning for children
- strengthen the caring capacity of families and communities to protect and care for OVC by provision of economic, material and psychosocial support, and development of life skills of children, parents and carers
- strengthen and support community based responses including engaging leaders in responding to OVC needs and cooperative support activities
- ensure that OVC have access to essential services including schooling, birth registration, health and nutrition services, safe water and sanitation, and appropriate placement services for children without family or community care¹⁴⁵

¹⁴¹ Also see Good practice principles in this section regarding programming for OVC and programming to address the wider socio-economic impacts of HIV/AIDS.

¹⁴² See Chapter 2.

¹⁴³ See also Section 3.5 Access and Equity.

¹⁴⁴ As at November 2003, 192 state parties (countries) have ratified (signed up to the obligations contained in) the CRC.

See key resources

- support children facing stigma and discrimination to cope with and respond to their situation¹⁴⁶
- pay particular attention to the roles of boys and girls, and women and men and address gender inequities
- build and strengthen partnerships with governments, donors, public sector and the full range of NGOs to coordinate responses and
- be sustainable and capable of replication to meet the long terms needs of OVC.¹⁴⁷

NGO impact mitigation programmes use a range of methods to address the social and economic impact of HIV/AIDS within communities.

NGOs need to work in partnership others or provide programmes that:

- strengthen household economic resources by improving access to microfinance – savings, credit, insurance to enable households to maintain income in times of crisis, in partnership with microfinancing organizations and creating employment and income generating opportunities
- ensure individuals can develop their skills base by access to education and vocational training to enhance income generating opportunities and
- enhance access to basic necessities such as safe food, water and appropriate housing.¹⁴⁸

NGOs advocate for a legal and policy environment that supports effective programming and promotes human rights.

NGOs need to advocate for review and reform of laws and policy to ensure:

- gender equity for women in accessing credit and income generating activities and property ownership
- universal birth registration
- protection of the inheritance rights of orphans and widows
- protection of children against neglect and abuse (physical, sexual, and emotional)
- prohibition of exploitative and harmful child labour
- availability and accessibility of social welfare support
- regulation of institutional facilities caring for children, including locating family and community based care as soon as practicable
- protection from discrimination
- access to education for both girls and boys, especially for girls and
- appropriate placement and guardianship of children who lack adequate adult care.

The *Declaration of Commitment on HIV/AIDS* explicitly acknowledges that in order to alleviate the social and economic impacts of HIV/AIDS, we must invest in sustainable development.

¹⁴⁵ Note the discussion of the inadequacies of institutional care in addressing the needs of orphans in *Strategic framework for protection, care and support of orphans and other children made vulnerable by HIV/AIDS* at page xx (add when final version available).

¹⁴⁶ See Section 4.3 Addressing Stigma and Discrimination.

¹⁴⁷ xx These programming principles and strategies are considered in detail in *Strategic framework for protection, care and support of orphans and other children made vulnerable by HIV/AIDS* and *Building Blocks: Africa wide briefing notes*, a series of booklets on psychological support, health and nutrition, economic strengthening, education and social inclusion, for communities working with orphans. See Key Resources.

¹⁴⁸ Also see Good practice principles on NGO advocacy below for discussion of mainstreaming HIV work in the context of development and humanitarian work; Section 2.6 Comprehensive and integrated responses and Section 4.5 Scaling up.

The *Declaration of Commitment on HIV/AIDS* calls for evaluation of the economic and social impact of the HIV/AIDS epidemic and development of multisectoral strategies to:

- address the impact at the individual, family, community and national levels;
- develop and accelerate the implementation of national poverty eradication strategies to address the impact of HIV/AIDS on household income, livelihoods, and access to basic social services, with special focus on individuals, families and communities severely affected by the epidemic;
- review the social and economic impact of HIV/AIDS at all levels of society especially on women and the elderly, particularly in their role as caregivers and in families affected by HIV/AIDS and address their special needs; and
- adjust and adapt economic and social development policies, including social protection policies, to address the impact of HIV/AIDS on economic growth, provision of essential economic services, labour productivity, government revenues, and deficit-creating pressures on public resources.¹⁴⁹

It is critical that global resource mobilization for the HIV/AIDS response does provide additional resources, are not merely shifting resources from development work to HIV/AIDS specific programming or vice versa. Resources for sustainable development initiatives need to continue and be expanded in order to support mainstreaming of HIV/AIDS within development programmes as are additional resources for specific HIV programming.

NGOs advocate for effective mainstreaming of HIV/AIDS including:

- transparency in resource allocations for sustainable development initiatives to support mainstreaming of HIV/AIDS within development programmes and additional resources for specific HIV programming
- strengthen the role of schools and educational system in building and reinforcing community capacities to prevent HIV infection, and in providing care and support for affected children and families, and in providing sexual health, sex and HIV education in school curricula and
- adapting development and humanitarian programmes, such as water and sanitation, food aid and agricultural development programmes, to take in to account vulnerability to HIV infection and impacts of HIV/AIDS.¹⁵⁰

NGO impact mitigation programmes are evaluated for effectiveness.

See Chapter 3 Operational Principles, Section 3.3 Programming planning which includes programme monitoring and evaluation.

NGOs advocate for adequate and appropriate research data to support an evidence - based approach to impact mitigation programming.

NGOs need to advocate for research that includes studies of the long term consequences of large numbers of orphans in societies and the effectiveness of various programmes in mitigating the impact of HIV/AIDS on OCV¹⁵¹ See good practice principles in advocating for adequate and appropriate research data to support an evidence-based approach to programming in section 4.1 HIV prevention, at page 33.

¹⁴⁹ *Declaration of Commitment on HIV/AIDS*, paragraph 68. See Section 2.7 Key Resources.

¹⁵⁰ See Oxfam resources on mainstreaming HIV/AIDS, in Key Resources. See also mainstreaming of HIV/AIDS in Section 4.5 Scaling up.

¹⁵¹ xx (Draft) *Strategic framework for protection, care and support of orphans and other children made vulnerable by HIV/AIDS*, at page 3 (xx add correct page reference when document finalised) see Key resources.

NGOs develop and maintain the necessary organisational capacity to support effective impact mitigation programming.

Staff and volunteers need to be supported to understand the complexities of the impacts of HIV/AIDS on PLHA and affected communities and develop the necessary knowledge and skills to design, deliver and evaluate impact mitigation programmes. Also see GPP in developing and maintaining organisational capacity to support effective programming generally outlined in section 4.1 HIV prevention, at page 34.

Key resources

UNICEF website provides a useful overview of the CRC, including the full text of the CRC.
<http://www.unicef.org/crc/crc.htm>

HIV/AIDS and the rights of the child, General Comment No.3, Committee on the Rights of the Child, March 2003,
[http://www.unhcr.ch/tbs/doc.nsf/\(symbol\)/CRC.GC.2003.3.En?OpenDocument](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/CRC.GC.2003.3.En?OpenDocument)

Children on the Brink: A Joint Report on Orphan Estimates and Program Strategies, UNAIDS, UNICEF and USAID, July 2002. http://www.unicef.org/publications/index_4378.html

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What religious leaders can do about HIV/AIDS: Action for Young Children and Young People, UNICEF, World Council for Religions for Peace and UNAIDS, November 2003,
http://www.unicef.org/publications/index_19024.html particularly Chapter 5.

Orphans and other children made vulnerable by HIV/AIDS: Principles and operational guidelines for programming, International Federation of Red Cross and Red Crescent Societies, 2002, <http://www.ifrc.org/what/health/tools/orphans.asp>

Approaches to caring for OVC: Essential elements for quality service, Institute of Primary Health for UNICEF, February 2001. http://www.unicef.org/evaldatabase/SAF_01-800.pdf

Africa's Orphaned Generation, UNICEF,
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Building Blocks: Africa wide briefing notes, a series of booklets on psychological support, health and nutrition, economic strengthening, education and social inclusion, for communities working with orphans, International HIV/AIDS Alliance, January 2003.
http://www.aidsalliance.org/_res/training/Toolkits/Building%20Blocks/English/Overview.pdf

Save the Children (UK), November 2001:

The role of stigma and discrimination in increasing vulnerability of children and youth infected with and affected with HIV/AIDS.

http://www.savethechildren.org.uk/temp/scuk/cache/cmsattach/1104_stigma.pdf and; *The Rights of Children and Youth Infected and Affected by HIV/AIDS: Trainers' Handbook*,
http://www.savethechildren.org.uk/temp/scuk/cache/cmsattach/1108_trainershandbook.pdf

Responses by Faith-Based Organizations to Orphans and Vulnerable Children: Preliminary Study of Six Countries in Africa, UNICEF, September 2003. xx (check availability, pdf not downloading) www.unicef.org/aids/FBOstudysummary.pdf

Oxfam resources to support mainstreaming HIV within the work of development and humanitarian organizations.

http://www.oxfam.org.uk/what_we_do/issues/hivaids/mainstreaming.htm

4.5 Scaling up

Overview

What do we mean by 'scaling up'?

The term 'scaling up' is used to encompass a range of strategies designed to increase the impact of programmes that aim to prevent HIV transmission and mitigate its effects, including mainstreaming HIV programmes within non HIV related programmes or services, expanding the geographical or population reach of programmes.¹⁵²

Giving the devastating scale and impact of HIV/AIDS in many developing countries, the need to develop and sustain responses of a sufficient scale to affect the dynamics of the epidemic is abundantly clear. While there is considerable expertise and knowledge about what works to prevent HIV transmission and meet the range of needs of PLHA and affected communities, many programmes have yet to become comprehensive in terms of coverage.¹⁵³

The extent to which NGOs can be proactive in scaling up, with sufficient time for reflection and planning in order to maximise impact and safeguard their organizational mission is critical.¹⁵⁴

There is much that can be learned from smaller scale initiatives that has wider relevance and application. However, scaling up NGO programmes is complex. It is critical to recognize and address the new challenges involved in the process of scaling up.¹⁵⁵ Increasing coverage alone is insufficient. In determining how best to bring to scale NGO programmes there is a need to recognize the dynamic relationship between a range of different factors such as the nature of the epidemic in a given context, the coverage needed, measuring impact, the costs involved and the implications of scaling up for maintaining programming quality.¹⁵⁶ Careful planning is needed to determine what programmes are capable of being bought to scale in order to maximise their impact. Resources need to be made available in a manner which supports the complexity of the process of scaling up. Pressures to meet escalating demand and/or government or donor expectations need to be carefully balanced with the need to maintain community ownership and realistic assessment of organizations capacity to expand their activities in order to ensure that the aim of scaling up is achieved.

There are a range of different strategies for scaling up including:

- expanding organizational size and/or scope

¹⁵² The range of strategies encompassed within 'scaling up' is considered below.

¹⁵³ See for example, *Report on the global HIV/AIDS Epidemic*, UNAIDS, 2000, cited in *A Question of Scale?*, See Key Resources and *Mobilization for HIV Prevention: A Blueprint for Action* (Key Resources – Section 4.1)

¹⁵⁴ *A Question of Scale?* at page 69.

¹⁵⁵ See the discussion of challenges associated with scaling up NGO efforts in *A Question of Scale?* pages 54 – 60.

¹⁵⁶ For example, in low prevalence countries, with an epidemic that is restricted to specific populations such as people who inject drugs, there is likely to be greater cost effectiveness and impact by scaling up targeted programmes for IDU, compared with high prevalence countries with a generalised epidemic.

- cascading and multiplication models involving provision of intensive training to groups that can provide training to others
- adapting concepts and models so that effective programme approaches can be adapted and replicated
- building practical working partnerships to develop joint initiatives to increase the reach and impact of programming through combined efforts
- integrating HIV/AIDS in to humanitarian and development work
- catalysing and supporting others by providing technical support
- decentralising services by transferring decision making and programme coordination from central location to a more local level
- influencing laws and policy that impact upon the effectiveness of HIV programming.¹⁵⁷

The strategies that are employed will vary depending on whether the organization concerned is an international, regional or in country Supporting NGO, or a national NGOs or local NGOs or CBOs. Supporting NGOs are likely to play a role in catalysing and supporting others to scale up programmes. This section provides good practice principles to guide NGOs efforts to scale up programmes considered in this Chapter: HIV prevention; treatment, care and support; addressing stigma and discrimination and impact mitigation. The good practice principles are to guide Supporting NGO in their efforts to support their partners in country to maximise the impact of programmes as they are expanded in scale.¹⁵⁸ In order to address the challenges of scaling up, here we examine both good practice principles in scaling up for NGOs generally, as well as outline good practice principles in scaling up that are specific to Supporting NGOs.

Good Practice Principles

NGOs work to scale up appropriate programmes to expand their impact, while ensuring their quality and sustainability.

In determining whether to scale up programmes, NGOs need to ensure that decisions to do so:

- are evidence-based by assessing epidemiological data and social/ behavioural research findings to identify the dynamics and stage of the epidemic in the given context
- involve PLHA and affected communities in participatory assessment to determine unmet need
- are informed by an assessment of the overall response by the range of organizations and institutions, including NGOs, public and private sector agencies within the particular context to identify unmet need
- determine which of the strategies for scaling up is most appropriate in the given context, such as whether the organization is best placed to address the unmet need, or whether efforts should be directed to advocating for or supporting other organizations or institutions to do so¹⁵⁹

¹⁵⁷ Each of these strategies is considered in *Expanding community action on HIV/AIDS: NGO/CBO strategies for scaling up* and *A Question of Scale?* Page 29 – 48, see Key Resources.

¹⁵⁸ These good practice principles draw upon the above two key documents. *A Question of Scale?* provides an in depth analysis of the complexities of and approaches to scaling up NGO programmes and organizations. *Expanding community action on HIV/AIDS: NGO/CBO strategies for scaling up* provides a practical guide to the process of scaling up. Each of these documents draws on NGOs experiences in scaling up.

¹⁵⁹ See good practice principles below in relation to NGOs advocacy efforts to support scaling up and scaling up in partnership, and the range of strategies outlined above which may mean NGOs are best placed to provide support to others in scaling up initiatives.

- maximise coverage and impact building on the organization particular strengths and experience
- are based on programmes that have been evaluated and are amendable to being scaled up effectively and
- take in to consideration whether organization has or can acquire the necessary financial and human resources and technical support needed to scale up.

When planning scaling up strategies NGOs need to ensure quality and sustainability by:

- assessing and responding to the implications for the organization of scaling up¹⁶⁰
- ensuring the necessary programming and organizational capacity exists including financial, technical, a supportive social and political environment to sustain the programme overtime¹⁶¹
- building on the strengths of community initiatives and fostering community ownership of programmes as they are bought to scale
- developing approaches that are sufficiently flexibility to address the diversity of need among vulnerable populations
- maintaining and developing the synergies between different programmes to strengthen the integration of programmes within the prevention care continuum¹⁶²
- determining an appropriate pace of change given organizational capacity, level of community mobilisation and time needed to implement scaling up strategies and
- establishing mechanisms for the collection and analysis of data to enable evaluation of the quality, sustainability and impact of programmes bought to scale.¹⁶³

Supporting NGOs need to assist their partner NGOs in scaling up by:

- developing and using transparent criteria for identifying partner NGOs capable of scaling up programmes
- ensuring clarity about and agreement to the nature of scale up envisaged at the outset including
- investing time and money in building capacity to support the scaling up
- allow and encourage NGOs to diversify their sources of support
- acknowledging and negotiating tensions among multilateral, governmental, NGO and donor goals, objectives and strategies for scaling up to ensure that the process of gaining support for scaling up does not undermine the independence and unique role of NGOs and
- actively promoting scaling up as a vital aspect of the global response to HIV/AIDS and facilitate exchange of information about it among local, national and international stakeholders.¹⁶⁴

¹⁶⁰ See good practice principles below regarding organizational capacity to support scaling up.

¹⁶¹ Also see Supporting NGOs role below in assisting partner NGOs, section 3.3 above and Good practice principles below regarding organizational capacity to support scaling up and advocating for a supportive environment for scaling up initiatives.

¹⁶² See also Section 2.6: Comprehensive and integrated responses and good practice principles that outline the application of this guiding principle to each of the areas of activity considered in this Chapter (Sections 4.1 – 4.4).

¹⁶³ See good practice principles below regarding monitoring and evaluation.

¹⁶⁴ *Expanding community action on HIV/AIDS: NGO/CBO strategies for scaling up* at page 38.

NGOs develop and maintain community ownership and organizational capacity to support scaling up of programmes.

Scaling up activities can have a significant impact on the internal dynamics of an organization.¹⁶⁵ When planning¹⁶⁶ and implementing scaling up strategies NGOs need to ensure:

- effective leadership and management of the internal implications of scaling up including assessment of financial and human resource needs, the appropriateness of the organizational structure, maintenance of organizational cohesiveness and continuity and that the pace of scaling up is appropriate to the organizational capacity over time
- timely and participatory processes that involve staff and volunteers in designing, implementing, monitoring and evaluating scaling up
- assessment of existing staff and volunteers capacity and provision of appropriate training and development based on assessed needs
- staff and volunteers are supported in their work including in the development of realistic work plans¹⁶⁷ and
- that the process of scaling up fosters a learning environment, including building capacity of staff and volunteers to document, reflect upon and analyse their experiences and communities experiences about what has and has not worked to inform organizational development and evaluation of programmes.

PLHA and affected communities involvement in the scaling up process and ownership of programmes is essential to effective scaling up. One of the challenges in scaling up is to balance the need to involve communities and remain responsive to community need, while being realistic about the necessary compromises to accountability and quality in order to expand the impact of the programme.¹⁶⁸ When planning and implementing strategies for scaling up NGOs need to ensure:

- scale-up is built on the strengths of community initiatives and sustaining community ownership of programmes as they are bought to scale
- consideration is given to fostering community awareness of those in the community whose needs are not being met by existing programmes, particularly those who may be isolated from access to programmes as a result of stigma and discrimination and
- involve PLHA and affected communities in design, implementation and evaluation of scaling up.

NGOs foster partnerships to enable effective scaling up of programmes.

Strategic partnerships are essential to scaling up programmes so that they are of sufficient scale to affect the dynamics of the epidemic. Given the underlying causes of vulnerability to HIV infection and impacts of HIV/AIDS, collaborative working partnerships between HIV specialist, health, development and human rights NGOs are critical to effectively responding to HIV/AIDS. Partnerships that integrate HIV within broader development, humanitarian and human rights work, build on existing infrastructure and supports a comprehensive response to addressing the causes of vulnerability to HIV infection and the impact of HIV/AIDS on poverty, access to food and education and gender inequities.¹⁶⁹ So too, partnerships between NGOs and governments, public and private sector agencies and donors are critical to generating

¹⁶⁵ *Expanding community action on HIV/AIDS: NGO/CBO strategies for scaling up*, at page 30.

¹⁶⁶ Also see Section 3.3 Programme Planning and Evaluation.

¹⁶⁷ Also see Section 3.2 Organizational Management

¹⁶⁸ *Expanding community action on HIV/AIDS: NGO/CBO strategies for scaling up*, at page 36.

¹⁶⁹ *A question of Scale?*, at page 37 – 38 considers mainstreaming of HIV/AIDS within the development sector.

support for and a coordinated approach to scaling up in order to improve synergies and develop economies of scale.¹⁷⁰

NGOs need to foster strategic partnerships to:

- developing consensus about major unmet need and identify those organizations or agencies best placed to address unmet need within a given context
- identify and address organisational and competitive obstacles to effective cooperation
- undertake joint scaling up initiatives in partnership to enable pooling of resources and expertise and build on existing relationships of trust between different organizations and within communities
- identify opportunities and act on or advocate for mainstreaming HIV programming within appropriate settings such as within the education system, poverty reduction initiatives and disaster relief programmes
- ensure integration of HIV with other related health initiatives such as sexual and reproductive health, malaria and tuberculosis and
- foster cross-fertilisation of organisational methods and approaches by sharing lessons learnt about successful programming and what is effective in scaling up those programmes.

NGOs advocate for a supportive policy environment to enable effective scaling up of programming.

NGOs advocacy efforts need to:

- increase understanding about effective responses to HIV/AIDS and the imperative to scale up these responses in order to impact upon the dynamics of the epidemic in a given context
- build support among key partners including government and donors about the appropriate pace of scaling up, the resources and co-ordination required to enable effective scaling up of responses
- increase understanding about, and application of, the knowledge derived from their experiences in scaling up programmes effectively and
- promote review and reform of laws and policy that hinder effective programming and undermine the rights of PLHA and affected communities, and how this in turn hinders effective scaling up of programmes to reach those most vulnerable.¹⁷¹

NGOs advocate for adequate and appropriate research data to support an evidence - based approach to scaling up of programming.

NGOs need to advocate for the necessary research data to support decisions about what programmes should be bought to scale and effective evaluation of the impact of efforts to scale up programmes. NGOs create opportunities to collaborate with research organizations and academic institutions to ensure research contributes to improving the evidence base about what works in scaling up programmes. See good practice principles in advocating for adequate and appropriate research data to support an evidence-based approach to programming in section 4.1 HIV prevention, at page 33.

¹⁷⁰ *A question of Scale?*, at page 42 – 45 considers Government – NGO relations in the context of ensuring a coordinated approach to scaling up.

¹⁷¹ See also good practices principles regarding advocating for a supportive legal and policy environment in sections 4.1 – 4.4.

NGOs monitor and evaluate programmes that are scaled up.

Scale-up requires that NGOs are able to monitor and evaluate larger and more complex programmes, often in partnership with other organizations. To do so, NGOs need to ensure that:

- data collection and evaluation methods enable an assessment of focus, coverage, quality, sustainability and impact and are in place before scaling up begins
- quantitative and qualitative indicators are developed and data is collected and used for programme evaluation
- PLHA and affected communities are actively involved in monitoring and evaluation
- organizational capacity is developed to support data collection and analysis
- there is agreement about monitoring and evaluation methods and indicators with donors
- when developing partnership initiatives, there is agreement about monitoring and evaluation methods and indicators including using standardized systems for data collection and analysis and
- the lessons learnt from scaling up are well documented and the experiences are shared within the organization, and with external partners, promoting on going process of improving scaling up efforts.¹⁷²

Key resources

Global Mobilization of HIV Prevention: A Blueprint for Action, Global HIV Prevention Working Group, July 2002 <http://www.kff.org/hivaids/200207-index.cfm>

Expanding community action on HIV/AIDS – NGO/CBO strategies for scaling up, International HIV/AIDS Alliance, June 200. International HIV/AIDS Alliance, see Reports and studies, Scaling up, <http://www.aidsalliance.org/eng/>

A Question of Scale? The Challenge of Expanding the impact of Non-Governmental Organizations' HIV/AIDS Efforts in Developing Countries, DeJong, J. Horizons and International HIV/AIDS Alliance, August 2001.

Oxfam resources to support mainstreaming HIV within the work of development and humanitarian organizations.

http://www.oxfam.org.uk/what_we_do/issues/hivaids/mainstreaming.htm

AIDS on the Agenda Adapting Development and Humanitarian Programmes to Meet the Challenge of HIV/AIDS, Holden S, December 2003

<http://62.173.95.217/oxfam/display.asp?isb=0855984694&TAG=&CID=>

Strategies for an Expanded and Comprehensive Response (ECR) to a National HIV/AIDS Epidemic, FHI, 2001.

<http://www.fhi.org/NR/rdonlyres/enfhxjmo7ekev5uuqtfvfwyzmvlfrkfcbe7zco6il4uovel5q5za3qm7xfirpq7zq4kthozmplqh/FHIECREnglish03july.pdf>

Scaling up antiretroviral therapy: Experience in Uganda, WHO, 2003

http://www.who.int/hiv/pub/prev_care/en/Uganda_E.pdf

Documenting and Communicating HIV/AIDS Work – A Toolkit to Support NGOs/CBOs, International HIV/AIDS Alliance, October 2001

¹⁷² Also Chapter 3 Operational Principles, Section 3.3 Programming planning which includes programme monitoring and evaluation.

[http://www.aidsalliance.org/_res/training/Toolkits/Documentation/Documentation%20\(Eng\).pdf](http://www.aidsalliance.org/_res/training/Toolkits/Documentation/Documentation%20(Eng).pdf)

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Chapter 5 – Appendices

5.1 Glossary

Acronyms

ABC – Abstinence, Be Faithful, Condoms

ARVs – antiretrovirals

CBOs – community based organizations

CRC – Convention on the Rights of the Child

FHI – Family Health International

GNP+ – Global Network of Positive People

ICASO – International Council of AIDS Service Organizations

ICCPR - International Covenant on Civil and Political Rights

ICESCR – International Covenant on Economic, Social and Cultural Rights

ICRW – International Centre for Research on Women

ICW – International Community of Women with HIV/AIDS

IDU – injecting drug use

MTCT – mother-to-child transmission

NGOs – non government organizations

NSPs – needle and syringe programmes

OHCHR – Office of the United Nations High Commissioner for Human Rights

OVC – orphans and children made vulnerable by HIV/AIDS

PLHA – People living with HIV/AIDS

STIs – sexually transmitted infections

UDHR - Declaration of Human Rights 1948

UNAIDS – Joint United Nations Programme on HIV/AIDS

UNFPA – United Nations Population Fund

UNICEF – United Nations Children fund

USAID – United States Agency for International Development

WHO – World Health Organization

Terminology

NGO

While it is not technically accurate, for convenience we use the term NGO to encompass the wide range of organizations that can be broadly characterised as ‘non – government’ including CBOs, Faith Based Organizations (FBOs), and organizations of affected

communities including people living with HIV/AIDS, sex workers, women's groups, among many others, who are active in the HIV/AIDS response.

Affected communities – this term is used to encompass the range of people affected by HIV/AIDS including carers, partners and family members of PLHA, orphans and children affected by HIV/AIDS and people at particular risk of HIV infection. Depending on the nature of particular epidemics, this may include women and girls, young people, sex workers and their clients, people who inject drugs (IDU), men who have sex with men (MSM), mobile and incarcerated populations.

Advocacy is a method and a process of influencing decision makers and public perceptions about an issue of concern, and mobilising community action to achieve social change, including legislative and policy reform, to address the concern.

Orphans and children made vulnerable by HIV/AIDS (OVC)

Children are affected by HIV/AIDS in a myriad of ways, not only when parents die of AIDS. There are increasing numbers of children living with sick or dying parents. Children are often required to drop of school to provide care, generate an income for the family. Many children are at risk of exclusion, abuse, discrimination and stigma.

5.2 Signatories to the Code

xx To be added to final text.

5.3 Acknowledgements

Project Steering Committee

Xx add names of steering committee members and key contacts for final version, including current and participating members and key contacts over the duration of the project.

<p>ACTION AID CARE USA Global Health Council GNP+ Grupo Pela Vidda Hong Kong AIDS Foundation ICASO</p>	<p>Ivoirian Network of PLWHA International Federation of Red Cross & Red Crescent Societies International Harm Reduction Association International HIV/AIDS Alliance World Council of Churches</p>
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Project staff and technical advisors

Project Manager and principal author of the Code: Julia Cabassi
Xx Add technical advice provided during the development of the Code

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