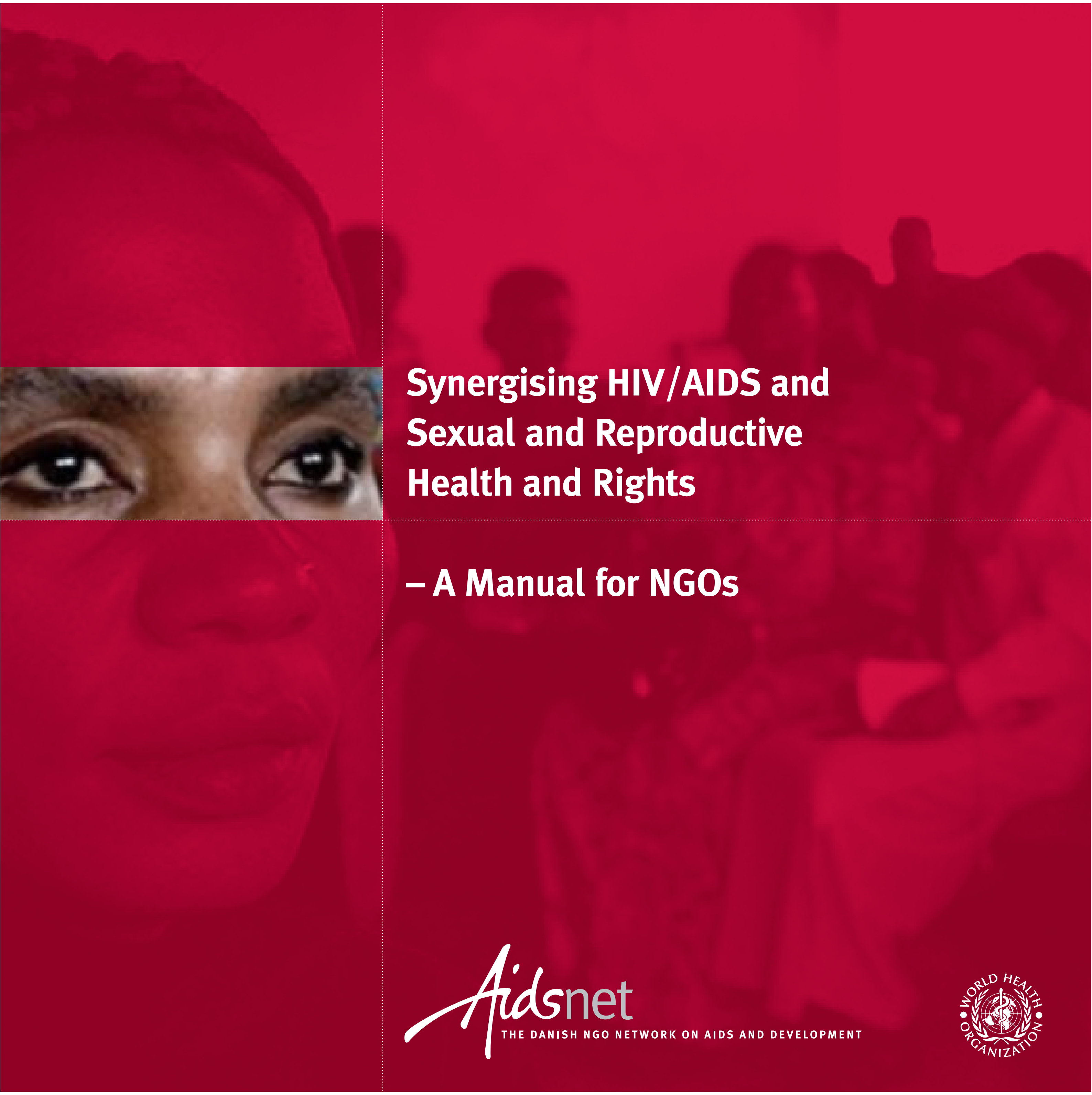

Synergising HIV/AIDS and Sexual and Reproductive Health and Rights

– A Manual for NGOs

Aidsnet
THE DANISH NGO NETWORK ON AIDS AND DEVELOPMENT

WORLD HEALTH ORGANIZATION

User's guide

Who is this manual for?

The development of this manual was requested by Danish non-governmental organisations (NGOs) in order to provide guidance to them as well as their partners in low-income countries on how NGOs can integrate HIV/AIDS-related issues with those of sexual and reproductive health and rights (SRHR). However, the manual can be used by staff and partners of any NGO with an interest in HIV/AIDS and related aspects of SRHR and other public health issues.

How should it be used?

The manual is meant to be a practical tool for NGOs working with HIV/AIDS and sexual and reproductive health and rights issues. It is not a textbook to be read from beginning to end, but rather a reference book, to be consulted when you need answers to specific questions and inspiration on how to deal with them in practice.

We have attempted to make the manual as user-friendly as possible, with explanatory boxes, concrete examples and cases of good practices or common approaches, and links to more information and other user-friendly resources and tools, including websites and existing guides and training manuals.

The various chapters have been kept in as similar a format as possible. In this way, it will be easier for users to familiarise themselves with the manual and be able to quickly locate the needed information.

This manual is meant to be shared as widely as possible. We therefore encourage that relevant sections be photocopied for further distribution. In addition, the content of the manual, together with other relevant documents, have been included on a CD-ROM. This provides users with the option of adapting or translating certain parts of the manual, for instance to make it more culturally sensitive, while maintaining the current layout. Finally, an electronic version of the manual can be downloaded from www.manual.aidsnet.dk. Other relevant information related to the development process of the manual will also be available on this website.

Structure of the manual

The manual is divided into five sections, of which this is the first. It is more explanatory in terms of introduction and key terms and issues.

The second section deals with the arguments and rationale behind integrating HIV/AIDS and sexual and reproductive health and rights. It emphasises important societal aspects of the framework for integrated HIV/AIDS and SRHR activities. The third section covers the most important health system factors while the fourth section of the manual addresses how NGOs can integrate HIV/AIDS with sexual and reproductive health and rights.

The fifth section consists of an overview of how the authors chose the relevant evidence for this manual. ☐

Second edition 2006

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Preface

The advent of the acquired immune deficiency syndrome (AIDS) has created extraordinary challenges for non-governmental organisations (NGOs) around the world.

This manual is for all who acknowledge that although HIV/AIDS is a unique challenge, NGOs can draw heavily on the wealth of already existing experiences accumulated by groups promoting sexual and reproductive health and rights, public health and other related issues. This manual seeks to facilitate, first and foremost, access to this body of evidence and, more specifically, demonstrate how NGOs can integrate key sexual and reproductive health activities with other HIV/AIDS work.

Aidsnet – the Danish NGO Network on AIDS and Development – believes that NGOs have a crucial role to play in the fight against HIV/AIDS in low-income countries. For many years, when the epidemic was regarded as particularly controversial, enveloped in prejudice and denial, civil society organisations were among the first to become involved in the care and support of HIV-infected people. Governments have, on the other hand, often shown that they are incapable of fully providing the required response to the HIV/AIDS crisis. NGOs, with their close connection to local target groups, know community leaders and are often able to act more quickly and flexibly. They can, therefore, contribute to strengthening the control of HIV/AIDS not only as health-care service providers but also in normative work, in policy-making and by holding governments accountable to their domestic and international commitments.

In a situation where the number of people in low-income countries without access to even basic prevention services or to existing treatment opportunities continues to grow, Aidsnet calls on NGOs and donors alike to increase their commitment to and financial support for the fight against HIV/AIDS, including the care, support and treatment of those already infected and those left behind by the pandemic.

But increased funding is not enough in and of itself. More is needed. Aidsnet is founded on a right-based approach that seeks to halt human rights abuses that fuel HIV risk, and to fully promote respect for the individual regardless of his or her serostatus, gender, sexual orientation, age or position in society. We further believe that it is only through the acknowledgement of people's right to participation that we can work together as equal partners. This entails that NGOs working from donor countries or in low-income countries must both fight stigma, discrimination, violence and other human rights abuses through their programmes as well as include people living with HIV/AIDS and other stakeholders in a meaningful way.

The idea for this manual emerged from Aidsnet's Strategy and Methodology working group. In the light of the need to accelerate progress towards achieving the Millennium Development Goals, the members of this group expressed a need for a practical set of tools and resources for all NGOs, regardless of the country they are based in, interested in the potential of combining HIV/AIDS and sexual and reproductive health and rights. Furthermore, such a manual, including a CD-Rom, complementary coaching activities and the establishment of a homepage at www.aidsnet.dk to collect lessons learned in relation to the work with the manual, is a multifaceted way to promote the three cross-cutting issues that Aidsnet seeks to promote: 1) a rights-based approach to HIV/AIDS; 2) the use of research and other evidence in NGO work; and 3) advocacy activities.

We live and work in a networked environment in which all 21 members of Aidsnet as well as our partners abroad are active in the prevention, mitigation and/or treatment of HIV/AIDS and to a varied degree also involved in the promotion of sexual and reproductive health and rights. Aidsnet strongly believes that if we work together as NGOs we will be able to offer a better and more coordinated response to the HIV/AIDS pandemic. Concretely, we would like to strengthen the collective sum of experiences and knowledge in our network with your feedback. I therefore encourage you to send your comments on this manual or other Aidsnet activities to us.

Good luck in your work.

Bjarne B. Christensen

Chairperson
Aidsnet – The Danish NGO Network on AIDS and Development

Abbreviations

AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal care
ARV	Anti-retroviral
ART	Anti-retroviral therapy
BCC	Behaviour change communication
CBO	Community-based organisation
FP	Family planning
FSW	Female sex worker
HBT	Homosexuality, bisexuality and transsexuality
HIV	Human immunodeficiency virus
ICPD	International Conference on Population and Development
IDU	Injecting drug user
IEC	Information, education and communication
KAP	Knowledge, attitudes and practices
MSM	Men who have sex with men
MTCTP	Mother-to-child transmission programmes
NGO	Non-governmental organisation
OI	Opportunistic infection
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child-transmission
RCT	Randomised controlled trial
RTI	Reproductive tract infection
SRHR	Sexual and reproductive health and rights
STI	Sexually transmitted infection
SWAp	Sector-wide approach
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNHCR	United Nations Refugee Agency
UNICEF	United Nations Children's Fund
VCCT	Voluntary confidential counselling and testing
WHO	World Health Organization

Acknowledgements

The manual was written by a team led by Jerker Liljestrand and including Jacqueline Bryld, Jeffrey Victor Lazarus and Lise Rosendal Østergaard. Furthermore, Catrine Christiansen, of the Nordic Africa Institute, contributed to the chapter on orphans and other vulnerable children. You can read more about the authors at the end of the manual.

A number of people and organisations have contributed actively to the development of this manual and Aidsnet is grateful for their willingness to share their expertise, their insights and their contacts with us.

A “South Panel” was established in order to ensure that the manual would meet the needs of Aidsnet’s partners abroad. This panel comprised, in alphabetical order, Edward Baralemwa, Pan African Christian AIDS Network; Cathy Doran, Local Community Competency Building in HIV/AIDS Prevention in Tanzania and Zambia (LCCBHA); Samira Luka, Coptic Evangelic Organization for Social Services Egypt; Elly Mugumya, Family Planning Association Uganda; Karen Sichinga, Churches Health Association Zambia; Shanta Shresta, LCCBHA; and Michael Usi, Adventist Development and Relief Aid Malawi. The South Panel was consulted at two stages of the preparation of the manual and provided written feedback to the team of authors. They shared many valuable resources and raised important concerns and solutions seen from a field perspective.

In addition to the South Panel, a group of technical reviewers was consulted at the end of the writing process to ensure the technical accuracy and currency of the text. This group of experts was selected on the basis of their knowledge of the body of literature for particular chapters as well as their current research in the field and included: Anita Alban, Calle Almedal, Delia Barcelona, Elizabeth Cantor-Graae, Jonathan Cohen, Pierpaolo de Colombani, Bertel Egerö, Mary Ellsberg, Niklas Eriksson, Andrew Green, Sam Guy, Valentina Hafner, Bent Hansen, Charlotte Kanstrup, Ulrich Laukamm-Josten, Joan MacNeil, Marjukka Mäkelä, Philippe Mayaud, Joel Nielsen, Peju Olukoya, Lisa Richey, Susan Rifkin, David Rivett, Helle Samuelsen, Jens Seeberg, Frants Staugård, Johanne Sundby, Esben Sønderstrup, Thomas Tufte, Marcel Vekemans, Klaus Witt and Bawa Yamba.

Finally, a background group was established by members of Aidsnet’s Strategy and Methodology working group. It included: Ib Bygbjerg, Department of International Health, Copenhagen University; Elsebeth Graugaard, DanChurchAid; Henny Hansen, Sex & Samfund; and Karen Schwartz Sørensen, Danish Missionary Council Development Department.

The staff of Aidsnet’s secretariat contributed to the work on the manual throughout the process, and we are particularly grateful to Ole Nørgaard for his comments on the chapter on evidence and for developing the Aidsnet online evidence-based search strategies (www.search.aidsnet.dk).

This manual was financially supported by the Danish Ministry of Foreign Affairs and is a co-publication with the Sexually Transmitted Infections/HIV/AIDS Programme of the World Health Organization Regional Office for Europe.

1. HIV/AIDS, sexual & reproductive health and rights and gender – intimately related

There is a strong but complex relationship between HIV/AIDS, sexual and reproductive health and rights, and gender. The fact that on a global scale, approximately 75% of all HIV cases are transmitted sexually and an additional 10% during pregnancy or through breastfeeding demonstrates that sexuality and thereby also gender are key issues to consider in order to understand the linkages. However, before discussing this relationship it is important to clarify the meaning of the concepts of HIV/AIDS, sexual and reproductive health and rights (SRHR), and gender, particularly as these concepts lay the foundation for this manual.

HIV

The human immunodeficiency virus (HIV) weakens the immune system by attacking and destroying certain white blood cells that are essential to healthy living. When HIV infects the human body, it usually replicates at low levels for many years. Most people infected with HIV look and feel healthy and can live for years without symptoms or only minor illnesses. They are infected with HIV, but they do not have AIDS. After a varying period of time, depending on the individual, the viral load reaches a significant level and this progressively leads to serious infections and other conditions that characterise AIDS.

AIDS

Acquired immune deficiency syndrome (AIDS) is a set of devastating infections that are a consequence of HIV infection. AIDS was first recognised as a new disease in 1981, when a number of young gay men in the United States were diagnosed with symptoms not usually seen in individuals with healthy immune systems. Many new cases were soon discovered of what appeared to be a disease associated with the breakdown of the body's immune or natural defence system. Within a few months, the same strange set of symptoms was being seen in female patients and haemophiliacs, and before long injection drug users and their non-drug-using sex partners and children were also being diagnosed with AIDS.

Although life-extending treatments exist, AIDS is a fatal disease. Researchers continue to try to develop vaccines and, ultimately, a cure. For the moment, however, prevention of transmission and lifelong treatment remain the only methods of control.

Gender

Gender is not a synonym for sex. Gender refers to the widely shared expectations and norms within a society about appropriate male and female behaviour, and roles. In most places there is a distinct and unequal difference between women and men's roles, access to resources and decision-making authority. Typically, men are seen as being responsible for the productive activities outside the home while women are expected to be responsible for activities within the home and family life.

The power balance in gender relations, that usually favours men, translates into an unequal power balance in heterosexual interactions. This results in male pleasure superseding female pleasure and men having greater control than women over when, where and how sex takes place. An understanding of individual sexual behaviour, male or female, necessitates an understanding of gender and sexuality as constructed by a complex interplay of social, cultural and economic forces.

Sexuality

Sexuality is distinct from gender yet closely associated with it. It is the social construction of a biological drive. An individual's sexuality is defined by whom he or she has sex with, in what ways, why, under what circumstances and with what outcomes. It is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. Ultimately, social rules, as defined by one's sex, age, socio-economic status, ethnicity and other factors, influence an individual's sexuality.

Reproductive health

According to the International Conference on Population and Development (ICPD) plan of action, reproductive health is:

> *"A state of complete physical, mental and social well-being in all matters relating to the reproductive system and to its functions and processes. It implies that people have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this is the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice. Reproductive health care also includes sexual health, the purpose of which is the enhancement of life and personal relations."*

Addressing the root causes of gender inequality and poverty

In the search for sustainable solutions to the continuous spread of HIV/AIDS and the lack of fulfilment of SRHR, it is important to identify and address the root causes. Gender inequality and poverty are two extremely important factors that both fuel the HIV/AIDS epidemic and act as structural barriers for improvements within these areas:

> *"Both sexual and reproductive ill health and HIV are rooted in the same social pathologies, including unequal gender relations, sexual violence, discrimination against sexual minorities, conflict and poverty"* (see www.countdown2015.org for more information on this issue).

Gender norms in low-income countries often dictate that women and girls should be ignorant and passive about sex. This greatly constrains their ability to negotiate safer sex or access appropriate services. Due to the often unequal power relations between men and women, women have much less access than men to key productive resources such as education, land, income, credit and employment, which significantly reduces their leverage in negotiating protection with their partners and greatly affects their ability to cope with the impact of ill health. Furthermore, many women and girls experience a high risk of unwanted pregnancies, violence and sexually transmitted infections. For men and boys, on the other hand, gender norms create social pressure to take risks, be self-reliant, and prove their manhood by having sex with multiple partners. Such norms expose men and boys to the risk of infection and create barriers to their use of HIV/AIDS prevention, care or support services.

In addition to gender inequality, it is important to recognise poverty as another important factor in the continuous spread of HIV infections and the current reproductive health situation. Poverty results in poor living conditions, malnutrition, poor health status and low levels of education, resulting in low levels of literacy which, when combined, can lead to low labour productivity. Furthermore, lack of economic resources is a hindrance for people to seek medical help from health-care facilities when required. The combination of malnutrition and vitamin A deficiency weakens the immune system and thereby increases the susceptibility to HIV and HIV transmission. Poverty can also be an important barrier to behaviour change for HIV prevention because it difficilitates the acquisition of the means to protection, such as condoms or clean needles and syringes. Poor households are also often politically and socially marginalised and can therefore be hard to reach with programmes addressing sexual behaviour change and harm reduction.

Finally, as an increasing number of women become infected, so do children, either during pregnancy or through breastfeeding. Poor people often do not access antenatal care and are more

Resources

- **DFID (2003): Sexual and reproductive health and rights: A position paper (2004) and UK's Call for Action on HIV and AIDS (www.dfid.gov.uk/pubs)**

These two papers review the current situation, describe challenges ahead and set out a thorough understanding the UK Department for International Development's (DFID) view of the future. One of the biggest donors in these fields in the world, DFID use the papers as the basis for planning their continued contribution to achieving the ICPD goals and to bilaterally and internationally tackle HIV/AIDS.

- **Askew, I and Berer, M (Nov 2003: 11(22)). "The Contribution of Sexual and Reproductive Health Services to the Fight against HIV/AIDS: A Review", *Reproductive Health Matters.* (www.popcouncil.org/pdfs/frontiers/journals/AskewBerer.pdf)**

This article is part of an issue of the journal Reproductive Health Matters which reviews and assesses the contributions made to date by sexual and reproductive health services to HIV/AIDS prevention and treatment, mainly by services for family planning, STIs and antenatal and delivery care. The article also describes other sexual and reproductive health problems experienced by HIV-positive women, such as the need for abortion services, infertility services and cervical cancer screening and treatment. It concludes that more integrated programmes of sexual and reproductive health care and STI/HIV/AIDS control should be developed.

- **Johns Hopkins University: "Reaching Men to Improve Reproductive and Sexual Health for all" (www.jhuccp.org/igwg)**

The guide demonstrates how to develop, implement and evaluate reproductive health programmes involving men and is aimed at reproductive health programme managers and

likely to give birth without appropriately skilled attendants, which means that most poor women do not receive the necessary treatment to prevent their children from becoming infected. Furthermore, they cannot afford to buy formula milk, and are therefore unable to avoid the risk of transmitting the virus by breastfeeding. And, if they do choose not to breastfeed, these women are often stigmatised as being both HIV positive and "bad" mothers.

Male involvement in addressing reproductive health and HIV/AIDS

For many years, reproductive health initiatives focused on women alone. However, during the last decade, the need for greater involvement of men has become increasingly clear. Changing men's attitudes and behaviour, by involving them in HIV/AIDS and SRHR programmes, is now recognised as a key strategy to improve the health of women and children. It is hoped that these programmes may help men improve their understanding of their own identity, masculinity, behaviour and reproductive health needs, and also help to promote gender equality. Increasing men's knowledge about sexually transmitted infections (STIs) including HIV, and safer sexual behaviour would clearly also have a positive effect on the lives of women. Furthermore, an improved understanding of reproductive health in general might make it easier for couples to engage in a dialogue about issues related to reproductive health and HIV protection.

technical staff of implementing agencies, governments and NGOs. Issues addressed include:

- male identity in adolescent men;
- policy initiatives and strategies for advocating male involvement;
- involving men through maternal and child health;
- men's right and empowerment in improving women's reproductive health;
- successful strategies for reaching men;
- tools and programmes for monitoring and evaluation.

■ **Centerwall E and Laack S, RFSU (2002).**
Young men as equal partners
(www.rfsu.se).

This book, available in English or Swedish, is based on RFSU's (the Swedish member association of IPPF) experiences with a project addressing men in Tanzania and Zambia. The project identified 14 topics considered to be of key importance to young men, and created a guidebook to be used in schools and other community groups that work with them.

■ **WHO (2003). Integrating gender into HIV/AIDS programmes:**
A review paper
(www.who.int/gender/hiv_aids)

This review paper provides background information and a suggested framework for considering the issues and challenges of integrating gender into programmatic and policy action. It also offers some programmatic examples of successful HIV/AIDS interventions that have addressed gender issues in a meaningful and significant way. It creates a picture of the ways in which gender influences women's and men's vulnerability in the epidemic and the range of potential programmatic responses.

STIs – an important link between SRHR and HIV/AIDS

STIs are important when dealing with HIV/AIDS as well as with SRHR. STIs can complicate pregnancies, by triggering spontaneous abortions and premature birth just to mention a few of the consequences. Today's STI patients risk becoming the HIV patients of tomorrow; but this risk may be reduced if they receive good advice from their health-care providers. Additionally, it is known that STIs facilitate the transmission of HIV, especially in girls and women. As it is several times more likely that a person with an untreated STI will become infected with HIV, STI and HIV/AIDS services should be integrated to a much greater degree (more detailed information about STIs is available in Chapter 16). For example, some young married women, who are difficult to reach by other means as they often do not attend school and are not working, can be reached through reproductive health services with HIV/AIDS related information and counselling. □

2. Mainstreaming HIV/AIDS, SRHR and gender

In the 1980s, before HIV/AIDS began to dominate the health agenda, the primary reproductive health focus of the health sector was on population health issues. As the scale of the HIV/AIDS epidemic became known, there was an increased focus on how HIV/AIDS could be integrated into the SRHR agenda. Today, this picture seems to be reversing, as HIV/AIDS is the topic receiving the most focus in terms of political commitment and funding. However, talking about HIV/AIDS and SRHR as if they were totally separate entities is counterproductive.

Why integrate?

The previous chapter presented the strong linkages between HIV/AIDS, SRHR and gender. The fact that there are several common entry points means that there is a great potential for synergies to grow out of an integrated approach to these three areas of work. Integration is an all-encompassing concept that, in principle, refers to the combination of different activities or services into the same programme, sector or facility. Simply put, it means that problems such as the spread of HIV or poor reproductive health should not be addressed piecemeal but through joint efforts. Sexually active individuals have a variety of social, reproductive and health-related needs that are best addressed through a package of care options. If that package is to be easily accessible by clients, it should ideally be offered at the same facility or at least with a strong referral system by providers that have been trained in both fields. This is beneficial for patients and more cost-effective for the health-care system.

But integration is not only about health-specific issues; it is also a question of people's right to have the entire continuum of their needs and desires respected. The unmarried young person might be sexually active and need contraceptives, for example. The HIV-positive woman, on the other hand, might be pregnant and need counselling on breastfeeding.

Additionally, integration is also a window of opportunity for advocacy. The spread of HIV/AIDS has put sexuality on the public agenda in a whole new way. It has become more legitimate to talk about sexuality and other issues related to SRHR. In that sense, it becomes important to use the opportunity that the current HIV/AIDS epidemic provides to also advocate for other aspects of SRHR.

This chapter will focus on mainstreaming as a strategy to expand the response to HIV/AIDS and SRHR in a long-term and sustainable way.

What does mainstreaming mean?

Mainstreaming is a process of change. It means analysing practices internally in an organisation and externally in the activities of the organisation. At the same time, practices and activities must be adapted accordingly to achieve the necessary change. In this manual we are interested in defining mainstreaming seen from an HIV/AIDS and SRHR perspective. In order to improve the understanding of the mainstreaming concept, it can be useful, as Sue Holden does, to distinguish between four types of work:

- AIDS and SRHR work is directly focused on AIDS prevention, care, treatment or SRHR. In other words, the work is distinct and implemented separately from other existing development and humanitarian work. Examples of AIDS and SRHR work are behaviour change interventions and support provided to networks of people living with HIV/AIDS or family planning clinics.
- Integrated AIDS and SRHR work is implemented along with or as part of development work. The focus is still on direct AIDS prevention, care, treatment or SRHR, but with the difference that the work is conducted in conjunction with other projects

or within wider programmes. One example is awareness-raising through education programmes or condom distribution to truck drivers as a component of a transport sector programme.

- Mainstreaming AIDS and SRHR externally refers to adapting development work in order to take vulnerability to HIV transmission and the impacts of AIDS and violations of SRHR into account. This could be an agricultural project addressing the needs of vulnerable households in an AIDS-affected community.
- Mainstreaming AIDS and SRHR internally is about changing organisational policy and practice in order to reduce the organisation's vulnerability to HIV infection and the impacts of AIDS and SRHR. The focus is on AIDS and/or SRHR and how these issues affect the organisation. This type of work has two elements: AIDS and SRHR work with staff (e.g. staff orientation and treatment options) and modifying how the organisation functions, for example, in terms of workforce planning, budgeting and methodology.

Why mainstream?

Mainstreaming is clearly not an overnight job, as the objective of mainstreaming is to make HIV a central part of development. In order to successfully mainstream HIV/AIDS and SRHR into development programmes much time and energy needs to be dedicated to the process. But is it necessary to mainstream?

There are many good reasons for mainstreaming, judging from the increase in the number of new HIV infections and the high incidence of early marriages, unattended deliveries and STIs, just to mention a few of the issues. It is time to further refine the strategies that are used to deal with these issues. So far, it is clear that if the "business as usual" approach is taken, with only specific, vertical HIV/AIDS and SRHR projects, it is highly unlikely that the situation will change to the desired extent.

Mainstreaming is also a way of changing the perception that HIV/AIDS and SRHR is solely a health sector issue. It has been repeatedly documented that a multisectoral response is required. This message is much easier to internalise onace a sector or project-specific analysis with an HIV/AIDS and SRHR lens has been undertaken. HIV/AIDS impacts all spheres of society and in some countries and regions it is drastically undermining development efforts in other sectors – mainstreaming HIV/AIDS and SRHR issues into development aid is therefore a must.

Box 1. What can your organisation do to mainstream HIV/AIDS?

- Put in place policies and practices that protect staff from vulnerability to infection and support staff who are living with HIV/AIDS and its impacts, whilst also ensuring that training and recruitment take into consideration future staff depletion rates, and future planning takes into consideration the disruption caused by increased morbidity and mortality.

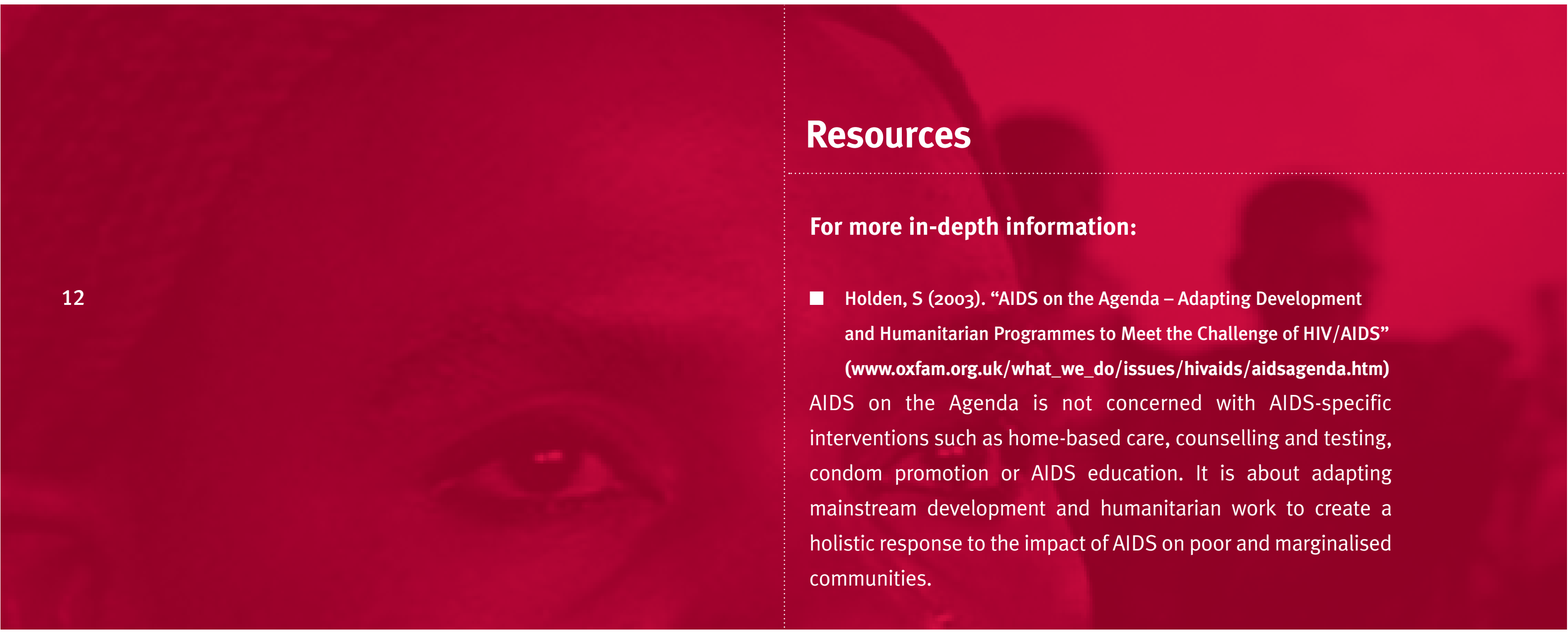
- Refocus the work of the organisation to ensure that those infected and affected by the pandemic are included and able to benefit from their activities.

- Ensure that the sector activities do not increase the vulnerability to HIV/STIs of the communities with whom they work or undermine their options for coping with the effects of the pandemic.

Source: Elsey and Kutengule (2003). "HIV/AIDS Mainstreaming: A Definition, Some Experiences and Strategies – A resource developed by HIV/AIDS focal points from government sectors and those that have been working on HIV/AIDS mainstreaming".

How can NGOs mainstream?

One of the prerequisites for successful mainstreaming is a strong commitment from the senior management of an organisation. This is important both in terms of allocation of budget as well as human resources as mainstreaming cannot be implemented



Resources

For more in-depth information:

- **Holden, S (2003). “AIDS on the Agenda – Adapting Development and Humanitarian Programmes to Meet the Challenge of HIV/AIDS” (www.oxfam.org.uk/what_we_do/issues/hivaids/aidsagenda.htm)**

AIDS on the Agenda is not concerned with AIDS-specific interventions such as home-based care, counselling and testing, condom promotion or AIDS education. It is about adapting mainstream development and humanitarian work to create a holistic response to the impact of AIDS on poor and marginalised communities.

Box 2. Oxfam: Mainstreaming HIV/AIDS in Malawi

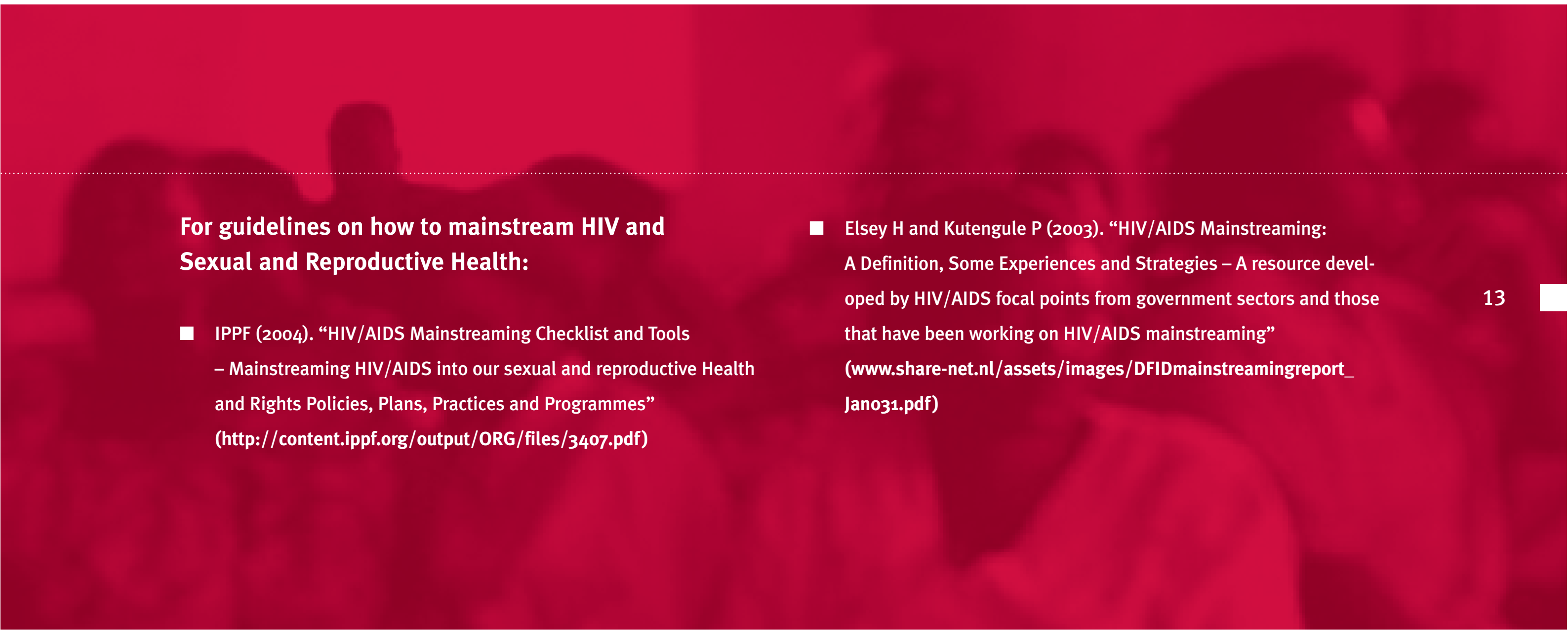
The NGO Oxfam has a great deal of mainstreaming experience. Oxfam has put a lot of effort into mainstreaming HIV/AIDS internally in the organisation as well as externally in their programmes both in their main office and their country offices. They have carried out many staff orientations and trainings and also have a full-fledged workplace policy in place for their staff. A good example of mainstreaming is the Oxfam country office in Malawi’s livelihoods programme. In this programme, the staff realised that certain activities were not accessible or relevant to families badly affected by shortages of labour and time brought on by AIDS. Women and girls in particular bear increasing burdens of farming and caring for others. Some activities were therefore modified to take into account how AIDS limits people’s ability to engage in agriculture. For example, in relation to animal husbandry less emphasis was put on goats and more on smaller livestock, which are easier to care for, can be kept near the home and create higher returns of food and cash. Similarly, other aspects were modified in relation to soil conservation and crop selection.

See www.oxfam.org.uk for more information.

without setting funds aside and acknowledging that such a process also requires extra staff time (see more about how to advocate for commitment in Chapter 25).

However, in practice mainstreaming is not implemented by the senior management. A general commitment by the staff is crucial to initiate such a process. It is important for staff to understand that mainstreaming is not just another administrative mantra but actually can and often will lead to many changes in personal perceptions of sexuality, gender and vulnerability to STIs including HIV. Mainstreaming can also have serious work implications as the design of certain project components might have to be adjusted while other components may even have to be removed.

A thorough understanding of the issues involved is required in order to facilitate this change. Staff training is the most common strategy; however, it is important that it does not take place as a one-off event; follow-up sessions must be carried out (see more regarding trainings in Chapter 26). This enhanced



For guidelines on how to mainstream HIV and Sexual and Reproductive Health:

- IPPF (2004). "HIV/AIDS Mainstreaming Checklist and Tools – Mainstreaming HIV/AIDS into our sexual and reproductive Health and Rights Policies, Plans, Practices and Programmes" **(http://content.ippf.org/output/ORG/files/3407.pdf)**
- Elsey H and Kutengule P (2003). "HIV/AIDS Mainstreaming: A Definition, Some Experiences and Strategies – A resource developed by HIV/AIDS focal points from government sectors and those that have been working on HIV/AIDS mainstreaming" **(www.share-net.nl/assets/images/DFIDmainstreamingreport_Jan031.pdf)**

knowledge about various HIV/AIDS or SRHR-related issues should make it easier for the staff to recognise the relevance of mainstreaming. □

3. Addressing HIV/AIDS: prevention, care and treatment, mitigation and stigma

When addressing HIV/AIDS it is important to acknowledge the links between prevention, care, treatment and stigma. Simultaneous treatment and prevention are necessary for an effective response to the epidemic. Clearly, on the one hand preventing new HIV cases is pivotal to stop this epidemic. On the other hand, caring for the people who are already infected and treating them to the extent possible is also necessary - be it for HIV or for opportunistic infections - and this is not always the case.

Voluntary confidential counselling and testing (VCCT) is a key intervention when it comes to linking HIV prevention and care and treatment for people living with HIV/AIDS (PLWHA). Counselling, regardless of whether the client is HIV positive or negative, provides an opportunity for HIV/AIDS related information to be communicated to the client. If the client is negative, it is important to try to ensure that the person remains negative, whereas if the client is positive, preventing transmission of the virus to others, as well as referring the client to care and support services and treatment options, if available, are crucial (for more information see Chapter 17 on VCCT).

Additionally, the involvement of PLWHA in delivering care and support services at the community level as well as in advocacy and behaviour change interventions can have a positive effect in terms of individual behaviour change and destigmatisation. This latter issue is of particular importance. As discussed below, PLWHA often face discrimination in their local community, but what is not always addressed is the stigma they face from health workers, who may refuse to treat them for fear of HIV.

This chapter provides an overview of some of the main issues within the field of HIV/AIDS prevention, care and treatment.

Box 3. Definition of behaviour change communication

Behaviour change communication (BCC) can be defined in the following way: “BCC is a multi-level tool for promoting and sustaining risk-reducing behaviour change in individuals and communities by distributing tailored health messages in a variety of communication channels”. BCC can be implemented through a peer-education approach, media campaigns or street dramas, just to mention a few channels, depending on the message and target audience.

Source: www.fhi.org

Strategies for HIV/AIDS prevention

People are vulnerable to HIV in different ways, some due to sexual transmission, others due to unsafe injection practices. People who are at different stages in life and who live in different environments need targeted prevention strategies in addition to larger-scale activities seeking to change the socio-economic environment that makes them vulnerable. One of the most frequently used strategies to prevent HIV has been to provide basic information about HIV and AIDS. However, information is not enough: changing the behaviour that puts people at risk is what is needed. For this reason, various messages have been promoted in different ways through behaviour change communication (BCC) interventions.

Sexual transmission can be prevented in a number of ways, often by combining various strategies. The ABC and D in HIV prevention is much used and often in a combination depending on the context. “A” stands for abstinence, not engaging in sexual intercourse. “B” means being faithful to one’s partner or reducing the number of sexual partners to monogamy. “C” refers to correct and consistent condom use, and “D” means delaying sexual initiation and is sometimes included in A. These four approaches have been widely used among young people, heterosexual adults and men who have sex with men (MSM).

The main HIV prevention strategies for injection drug users (IDUs) have been needle and syringe exchange programmes (harm reduction) as well as drug treatment/opioid substitution therapy with methadone, buprenorphine or other substitutes. The purpose of harm reduction programmes is to collect contaminated needles and syringes from IDUs and provide clean ones in exchange. In many countries, this type of programme has been met with much hostility from governments, as drug use is illegal and harm reduction is seen as promoting drug use. However, it must be recognised that IDUs will continue their injection practices with or without clean needles, due to the drug addiction; it is therefore clearly better to provide drug users with the means to protect themselves and sexual partners – in this way the rates of HIV transmission as well as hepatitis B and C can be reduced significantly.

Drug substitution therapy is another proven strategy which aims at reducing HIV transmission. This is a medically supervised treatment of individuals, which aims at helping IDUs to abstain from using illicit drugs such as heroin. Furthermore, opioid substitution treatment reduces unsafe injection practices, reducing the risk of HIV transmission.

Prevention of mother-to-child transmission (PMTCT) is a strategy to prevent HIV transmission to infants from their mothers during pregnancy, delivery or as a result of breastfeeding. Scaling up HIV prevention services for women of childbearing age, access to VCCT for pregnant women, comprehensive reproductive health services and access to ARVs such as nevirapine are crucial elements of PMTCT.

Ensuring blood safety by screening all blood transfusions for HIV is also a central HIV prevention strategy which was tackled in the early years of the epidemic, but remains a recurring problem in some countries. For more about blood safety, see Chapter 20.

Care, support and treatment of HIV/AIDS

The aim of HIV/AIDS care, support and treatment is to improve the quality of life of PLWHA, their families and communities as well as to mitigate the impact of the AIDS epidemic. Comprehensive care is about responding to the needs of PLWHA in a holistic way. It involves the provision of a variety of informational material, resources and services to address a range of needs, which are by no means confined to the medical sphere. Comprehensive care includes information and counselling, clinical care and treatment, home-based care and family counselling.

People who are ill with AIDS are often cared for by family members, particularly women. As women are often responsible for the reproductive and private sphere, they are usually the primary caregivers, and having an AIDS patient in the household increases their daily workload substantially. Being a caregiver is a very emotional and difficult task. It is hard work looking after someone who is ill, and often the caregiver may not even have time to take care of his or her own needs.

Stigma and discrimination

Addressing stigma and discrimination is an extremely important element of care and support of PLWHA. The stigma attached to HIV/AIDS infection often deters PLWHA from openness about their HIV status.

Stigma can lead to discrimination against PLWHA, who risk being isolated, judged or blamed for being infected. For example, PLWHA are often rejected or treated badly at work, in hospitals and health-care facilities as well as by their community, friends and family.

PLWHA are automatically linked to behaviours that are disapproved of by society. It is often assumed that men who are infected with HIV are homosexual, have had sex with female sex workers (FSWs) or are IDUs. Women who become infected are assumed to be promiscuous or FSWs. In many countries there is a widespread belief that “good” people will not contract HIV and

Resources

- **UNAIDS (2004). “Report on the global AIDS epidemic” (www.unaids.org)**

This report and regular updates, also by country, are key resources for both HIV/AIDS trends as well as analytical studies on the current situation,

- **WHO. Treating 3 million people by 2005 initiative. Making it happen (www.who.int/3by5/publications/documents/isbn9241591129/en/)**

This WHO strategy aims to set out in clear detail how life-long antiretroviral treatment can be provided to an additional 3 million people living with HIV/AIDS in poor countries by the end of 2005. Core principles include urgency, equity and sustainability. The strategy was the first international document to make clear that treating HIV/AIDS, and not just preventing it, must be a top priority. There are numerous related documents at the WHO and UNAIDS websites.

- **Global HIV Prevention Working Group (2002). “Global mobilization for HIV Prevention – A Blueprint for Action” (www.kff.org/hivaids/200207-index.cfm) and “HIV Prevention in the Era of Expanded Treatment Access” (2004)**

The Global HIV Prevention Working Group is an international panel of nearly 40 leading public health experts, clinicians,

that only people engaging in immoral behaviour risk infection.

The process of stigmatisation is reinforced by the tendency of PLWHA to make themselves invisible and deny their condition as they have internalised society’s prejudices and are ashamed of their condition. This is known as self-stigmatisation. Self-stigmatisation allows society to deny that there is a problem, leaving the PLWHA without adequate care and treatment.

Stigma (and self-stigmatisation) and discrimination can also keep people from getting tested, contribute to them infecting others and prevent people who are infected from receiving adequate care and treatment. It also dramatically decreases the quality of life of PLWHA and can lead to depression and even suicide.

Box 4. Why Antiretroviral Therapy (ART)?

- ART prolongs lives, making HIV/AIDS a chronic disease, not a death sentence. Affluent countries have seen a 70% decline in HIV/AIDS deaths;
- ART holds the potential to help calm fears and change attitudes towards PLWHA;
- ART, as part of a prevention plan, can significantly reduce HIV transmission;
- ART, once very costly, is now much more affordable;
- ART can reduce overall health-care costs and restore quality of life.

Source: www.who.int/3by5/about/en/

Treatment

Treatment is a key element of care and support for PLWHA and should not only be seen in terms of drug treatment but rather as a form of care and support that provides relief and improves well-being. Anti-retroviral (ARV) treatment is currently the only life-prolonging drug treatment for PLWHA, although it is unavailable to many. Despite the fact that the prices of ARV drugs have dropped dramatically during recent years, they are still very costly and in most low and middle-income countries still not widely available.

It is important to remember that treatment for HIV is lifelong. If

biomedical and behavioural researchers, and people affected by HIV/AIDS. These two reports seek to inform global policy-making, programme planning and donor decisions on HIV prevention, and advocate for a comprehensive response to HIV/AIDS that integrates prevention and care.

- **Nordic Africa Institute (2005). Models for Life: Advancing antiretroviral therapy in sub-Saharan Africa. Current African Issues No. 31. (www.nai.uu.se/)**

This working paper discusses how NGOs can promote equitable access to antiretroviral therapy in sub-Saharan Africa. Based on two workshops organised by Aidsnet, the Nordic Africa Institute and Roskilde University the paper shows how antiretroviral therapy represents a window of hope but also what a challenge it is to work with holistic approaches to HIV/AIDS prevention, care and treatment.

- **Open Society Institute (2004). Harm Reduction: Questions and Answers. (www.soros.orginitiatives/ihrd/articles_publications/publications/qa_20041123)**

Using scientific evidence, "Harm Reduction: Questions and Answers" briefly explains why harm reduction programmes effectively reduce the individual and societal damage caused by drug use, with the main goal of preventing the spread of infections, especially HIV/AIDS.

treatment is not taken as prescribed and continuously, patients can build up resistance to drugs. It is therefore extremely important to consistently follow the treatment plan as designed, including taking all medications properly for the full duration of the treatment. NGOs can play an important role in ensuring that this is done, in addition to ensuring the availability of ARVs.

Adherence requires the patient to actively participate with the health-care provider in developing and maintaining the treatment plan. The patient takes an active role in implementing the treatment plan and shares responsibility with the provider for clinical outcomes.

While ARV therapy is an important part of improving well-being, treatment of opportunistic infections is equally important as most people are put on ARVs at a late stage of their HIV infection, by which time they will already have experienced many recurring infections.

Scaling up prevention, care and treatment

Globally, fewer than one in five people at risk of HIV infection have access to proven HIV prevention interventions: VCCT, condom promotion, treatment of STIs, drugs and strategies to prevent mother-to-child transmission and harm reduction for IDUs. Access to ART is even lower, with only slightly over 700,000 of the estimated six million people in need of treatment in low and middle-income countries currently receiving it. Clearly, a drastic scaling-up of interventions is required and will be a pre-condition for combating the AIDS pandemic effectively. However, the current scale-up has shown that it not only requires a drastic increase in funding but also requires political will and commitment as well as a strong health system. Building local capacity to respond to the pandemic is one of the main challenges, and one of the most difficult to achieve, particularly in high-prevalence countries, as efforts are constantly undermined by the continuous AIDS-related deaths.

Reducing the impact

HIV/AIDS is having a grave impact on countries with a high prevalence both at household and community levels. As noted in the previous chapter, one of the root causes of the spread of HIV is poverty. However, it is a vicious spiral as the impact of AIDS further increases poverty. Households affected by AIDS suffer the loss of productive labour, income and food reserves, and savings are spent on health-care and funeral costs. In general, financial resources diminish as HIV progresses into AIDS, and households might have difficulty in continuing to purchase seeds and fertilizer and might take their children out of school, as the children are required to work either in the homes or in the fields.

In order to mitigate some of the impacts, it is necessary to consider ways to reduce the overall demand on labour both in the production of foodstuffs and in other household activities. Small loans, known as micro-credit schemes, could also be considered as a way to help maintain, repair and restock both household and productive supplies. Analysing the specific context is important before choosing the specific strategies and interventions, as it should correspond to the way HIV is spreading and affecting the community.

In the most severely hit countries, all organisations – public and private universities, businesses and ministries – need to implement their own HIV/AIDS policies to help mitigate the impact of AIDS, taking into account the expected loss of human resources. ☐

Societal aspects

The seven chapters in this section are:

This section of the manual addresses the societal aspects of HIV/AIDS. Whereas the previous chapters examined the big picture – how to integrate HIV/AIDS and sexual and reproductive rights, as well as aspects of prevention and treatment of HIV/AIDS – the chapters in this section look at basic, guaranteed rights, be they for adolescents, sexual minorities or adults, in daily life or emergency situations. Most scientists and activists today agree that HIV/AIDS can no longer be seen through a medical lens alone; societal aspects, including poverty, gender inequities and other violations of rights form the underlying causes of the HIV pandemic. That is why these aspects are given a high priority throughout this manual.

4. The rights-based approach

Often, when speaking of the importance of effective public health policy and practice we do not have a legal basis for doing so, i.e. one founded in national and international law, binding conventions and declarations. The legal basis for effectively integrating reproductive health and HIV/AIDS may be found in a range of human rights instruments, some of which are described in Box 5. It has been said that in the case of HIV/AIDS, protecting human rights – including the full range of reproductive rights – is essential to an effective response to the epidemic. A rights-based approach to HIV/AIDS means curbing abuses that increase HIV risk (such as sexual violence, harmful traditional practices and censorship of HIV/AIDS information), protecting political freedoms so that societies can respond effectively to the epidemic and ensuring access to HIV/AIDS services and information without discrimination based on age, class, gender, geographic location, ethnicity or ability to pay.

In addition to some of the core human rights instruments listed in Box 5, more recent documents, particularly the Beijing Platform for Action of the World Conference on Women (1995), the Declaration of Commitment of the UN General Assembly Special Session on HIV/AIDS (UNGASS) in 2001 (see Box 6), and the UN's International Guidelines on HIV/AIDS and Human Rights reflect a broad international consensus on the linkage of reproductive rights and HIV/AIDS in particular, in addition to addressing other aspects of each field.

Although not legally binding, the International Conference on Population and Development Programme of Action ("the Cairo Programme") is the key instrument guiding organisations working with sexual and reproductive health and rights, and marks an important step in recognising reproductive rights internationally. It upholds the right of individuals to decide freely the number, spacing and timing of their children and to have the information and means to do so. It further expresses the right of men and women to be informed about and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, which are not against the law, and specifically addresses HIV/AIDS throughout the document.

In spite of the availability of these instruments and others, it can be difficult for non-practitioners of human rights to understand, interpret and apply them to current situations. Many of the human rights guarantees expressed in international instruments have been modified and interpreted through court cases, official reviewing processes, exceptions and state practices, often but not always noted at the time of signing. While countries are generally expected to adopt the provisions of legally binding conventions into their own national legislation, they do not always do so and may make changes, even by interpreting the original language differently during translation. Not all countries have signed or ratified international instruments, and it can be difficult to interpret the legal obligations of non-parties. Even where countries have ratified conventions, no rights are "written in stone" as they should be applied in the national context.

Box 5. Key rights documents and where to find them

- International Conference on Population and Development Programme of Action **(www.unfpa.org/icpd/summary.htm);**
- Universal Declaration of Human Rights **(www.un.org/Overview/rights.html);**
- Covenant on Civil and Political Rights **(www.unhchr.ch/html/menu3/b/a_ccpr.htm);**
- Covenant on Economic, Social and Cultural Rights **(www.unhchr.ch/html/menu3/b/a_cescr.htm);**
- Convention on the Elimination of All Forms of Discrimination Against Women **(www.un.org/womenwatch/daw/cedaw/);**
- Convention on the Rights of the Child **(www.unhchr.ch/html/menu3/b/k2crc.htm)**

What can be perceived as an entitlement in one country might therefore not be available in another.

One added value of a rights-based approach is that NGOs and individuals can use certain procedures to hold governments (and even some non-state actors) accountable to international human rights law, which includes the promises undertaken in international conventions. Among the legally recognised human rights guarantees that are relevant to the integration of HIV/AIDS and reproductive health are the right to information about health issues, the right to express oneself freely about public health policy (including about controversial issues such as abortion), the right to confidentiality and voluntariness in HIV testing, the right to non-discrimination in access to health information and services, freedom from gender-based violence and the right to benefit from new scientific technologies and research findings. Each of these rights is both guaranteed in itself and linked to the right to the enjoyment of the highest attainable standard of physical and mental health, which is specifically recognised in article 12 of the International Covenant on Economic, Social and Cultural Rights.

Box 6. Rights in the UNGASS Declaration

The Declaration of Commitment on HIV/AIDS adopted at the UN General Assembly Special Session on HIV/AIDS (UNGASS) in June 2001 fully integrates human rights within the goals and targets that Member States have committed themselves to undertake in the HIV/AIDS response. Governments pledged:

> *"...by 2003, to enact, strengthen or enforce as appropriate legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups; in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic."*

For further details of the commitments made by countries at UNGASS, see: www.unaids.org/ungass/en/global/ungass00_en.htm

Examples of key rights

■ The right to health

As noted above, the right to the enjoyment of the highest attainable standard of physical and mental health is recognised in article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). The World Health Organization has similarly called for “the attainment by all peoples of the highest possible level of health”. Health is defined in WHO’s Constitution (1948) as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. The WHO Constitution further states that governments have a responsibility for the health of their people.

Sexual and reproductive health are essential elements of the right to health, as they are inseparable from men and women's overall well-being. The content of the right to health is elaborated in General Comment 14 of the Committee on Economic, Social and Cultural Rights, the UN body responsible for overseeing implementation of the ICESCR.

■ Children’s rights

States parties to the Conventions listed in Box 5, particularly the Convention on the Rights of the Child, are obliged to protect a full range of children’s rights linked to sexual and reproductive health, including the child’s very right to survival and development. Children enjoy the right to complete information about HIV/AIDS and sexual health, to reproductive health services without discrimination and to protection from abuse and exploitation that increase their HIV risk. The rights of the child to survival and development are also linked to the rights of women: the threat to women's lives posed by lack of reproductive health care, including prevention of mother-to-child transmission of HIV, jeopardises the health and development of children.

■ Abolishing traditional practices prejudicial to the health of women and children

Human rights conventions require states to take all effective and appropriate measures toward abolishing traditional practices that are prejudicial to the health of children. These may include the practice of female genital mutilation, which can increase biological vulnerability to HIV and other STIs, as well as practices that subordinate women such as child marriage, wife inheritance and bride price. Traditional inheritance laws, which are often reinforced by national laws and constitutions, can also increase women's HIV risk by stripping them of their property on the dissolution of marriage. Women who lack access to property or who are economically dependent on men are often forced into risky sexual situations to survive.

■ The right of equal access to health care

In many countries, violence, discrimination and lack of economic independence can impede women's equal access to health services and information. Often, women refuse to seek HIV testing out of fear of retaliatory violence by their husbands on disclosure of their HIV status. Unequal access to education may also limit women's and girls' health seeking behaviour. Parties to international human rights conventions are required under international law to take all appropriate measures to eliminate barriers to health care, and to ensure women's equal access to health-care services, including those relating to family planning.

■ The right to enjoy the benefits of scientific progress

Under international law, all people have the right to enjoy the benefits of scientific progress and its applications, which should be interpreted to include reproductive health technologies such as modern family planning methods, condoms for HIV prevention (including female condoms), and HIV vaccines and microbicides, if and when they become available.

How do you ensure rights?

I. Important challenges

There are many conflicting opinions about what is protected under human rights law, and moreover what should be protected. It is best to have an expert in international human rights law (as well as the domestic law of the country in which you are working) review your material/arguments when you are referring to legal rights. NGOs can advocate for the right of access to voluntary confidential HIV counselling and testing or universal access to reproductive health-care services because it is recognised in international instruments such as the ICPD Programme of Action and the Beijing Platform of Action. Recognised human rights that apply to the health context include the right to privacy, confidentiality and freedom from coercion.

II. Set goals and objectives

What is the message you want to get acoss? Are you trying to raise awareness, change the law or both? Remember, most of the activities you will carry out have been tried elsewhere, so draw on international experience such as in the resources below.

III. Identify target audience and relevant duty bearers

Depending on your objectives, you must decide on your primary target, e.g. a government body, the general public, the media or multilateral bodies. In the case of the former, explicit reference to conventions and national and international laws that the country has signed could be made (see Chapter 25 on advocacy).

IV. Establish alliances with duty holders

If possible and strategically relevant you can include the relevant target groups in your strategy so that they are not only represented but also "on board", to the extent that this is realistic (see Box 7).

V. Violation of rights

Both internationally, and often nationally, there are mechanisms to monitor and report human rights violations. Often, violations are found in unequal access to health services, but violations may also occur in the design of services or in state conduct that impedes access to services, denying young people or unmarried women access to family planning, for example. Some countries have, for example, a national human rights commission, a patient rights legal framework or other forum to report suboptimal care. NGOs can help build these organisations or strengthen them where they exist.

■■■ Entry points for NGOs

■■One of the main ways NGOs can take action on human rights is to integrate a rights-based approach into their existing activities. Making existing services more "client-centred" is one way to this, and is recognised in the ICPD Programme of Action as a component of a rights-based approach. In HIV/AIDS interventions, this would mean involving HIV-positive individuals and other often marginalised stakeholders in programme design and evaluation.

■■Another approach to human rights advocacy is to advocate for the repeal of laws, policies and attitudes that inhibit the prevention and treatment of HIV. Draw special attention to laws and policies that discriminate on the basis of sex or sexual orientation. It is sometimes effective to argue that such laws threaten the realization of national and international development goals, such as goal 6 of the Millennium Development Goals (www.

Box 7. Components of a rights-based approach to reproductive health

Participation:

- Increasing access to information on reproductive rights in order to provide people with choices and a sense of entitlement to quality services as a basis for participation;
- Ensuring that poor and especially vulnerable persons participate actively in setting government priorities and standards
- Supporting women and other affected groups, including people living with HIV/AIDS, in participating in the provision and monitoring of quality sexual and reproductive health care; and
- Working with community leaders to protect reproductive rights.

Inclusion:

- Targeting poor, vulnerable and excluded groups in countries with the largest burden of sexual and reproductive health problems;
- Working with men and boys to tackle violent or discriminatory behaviour and increase their understanding of women's rights; and
- Addressing discriminatory attitudes and practices among service providers by increasing health workers' understanding of reproductive rights whilst upholding the rights of the service providers themselves.

Obligation:

- Reforming laws, policies and practices that contribute to poor sexual and reproductive health;
- Enacting and enforcing laws and policies that protect women's health, such as prohibitions against sexual violence and marital rape, discrimination in access to health care, education and other social goods, and harmful traditional practices such as child marriage and female genital mutilation;
- Enacting and enforcing anti-discrimination laws that enable vulnerable groups to access services on an equal basis;
- Building the in-country capacity to advocate for sexual and reproductive health and rights

Source: Adapted from "Sexual and reproductive health and rights – A position paper", DFID, 2004 developmentgoals.org), which is included in your advocacy tools. National laws should also protect the human rights of people living with HIV/AIDS, including their right of access to affordable highly active antiretroviral therapy.

■■Faith-based NGOs and churches, which often engage and involve many people, potentially have a strategic role in promoting human rights in relation to HIV/AIDS and SRHR. This is especially the case in countries where they are the leading providers of health care.

■■Documenting human rights abuses and ensuring that governments respect the international agreements they have signed is a central element of human rights advocacy. Be a watchdog and report to the press and the government agencies directly responsible when you can document that the government

Resources

- **Cook RJ, Dickens BM and Fathalla MF (2003).**
  Reproductive health and human rights. Clarendon Press, Oxford.

This is arguably the most comprehensive book on reproductive health and human rights. It seeks to help advocates, practitioners and policy-makers understand the essential medical, legal, ethical and human rights issues related to sexual and reproductive health, and to apply them to their own settings.

- **OHCHR and UNAIDS (2003). "HIV/AIDS and Human Rights**
  International Guidelines," including Revised Guideline 6,
  Access to prevention, care and support.
  (www.unaids.org).

These guidelines, developed in cooperation with NGOs and groups of people living with HIV/AIDS, provide policy guidance to governments seeking to promote and protect respect for human rights in the context of HIV/AIDS.

- **UNAIDS (1999). "Handbook for Legislators on HIV/AIDS,**
  Law and Human Rights: Action to Combat HIV/AIDS in View
  of its Devastating Human, Economic and Social Impact."
  Geneva, UNAIDS.

While this handbook seeks to assist parliamentarians and other elected officials in promulgating and enacting effective legislation to fight AIDS, it is also a very useful tool for NGOs. It provides examples of legislative and regulatory practices gathered from around the world. Best practices are given for each of the 12 guidelines contained in the International Guidelines on HIV/AIDS and Human Rights (see above).

- **International Planned Parenthood Federation (IPPF) (1996).**
  Charter on Sexual and Reproductive Rights, London.

The IPPF Charter lays out the 12 key rights in the field of sexual and reproductive health. Each right is sourced to the relevant international instrument, making this short, handy document a key resource for NGOs. The IPPF website (www.ippf.org) addresses the rights-based approach in-depth and provides a multitude of guidelines, glossaries and other tools for NGOs.

- **RFSU (2004). Reality Counts: Focusing on Sexuality and**
  Rights in the Fight against HIV/AIDS (www.rfsu.se)

This book consists of a collection of articles about HIV/AIDS around the world. It connects what was adopted at the International Conference on Population and Development in this respect to the Millennium Development Goal of halting the spread of HIV/AIDS and shows that it is essential to embrace SRHR for its achievement.

- **IPPF, Siecus, Planned Parenthood Federation of America Understanding Religious and Political Opposition to Reproductive Health and Rights, 2004 (www.siecus.org/inter/Pol_Rel_Opp_Guide.pdf).**

This resource addresses key arguments and tactics opposing reproductive health and rights and counters them with useful facts. For example, in responding to opposition to condom promotion in the section “Restricting HIV prevention”, the guide presents arguments based on statements from UNAIDS, the Fourth World Conference on Women and the Convention on the Rights of the Child.

- **Canadian HIV/AIDS Legal Network. Programming HIV/AIDS: A human rights approach, 2004. (www.aidslaw.ca/Maincontent/issues/discrimination/ rights_approach/international.htm)**

Although focused on Canada, this book is also relevant for development and community-based organisations in other countries. It is designed to facilitate the integration of human rights approaches into development programming on HIV/AIDS. To do this, it identifies four key principles of a human rights approach to development, and examines how they apply to HIV/AIDS programming. Practical aspects of programme design, implementation and evaluation are discussed, and useful checklists provided.

- **Save the Children Sweden. Promoting Rights-Based Approaches: Experiences and Ideas from Asia and the Pacific (www1.rb.se/Shop/Products/Product.aspx?ItemId=1188)**

This book provides a general overview of rights-based approaches from Asia and the Pacific. This is followed by a review of experiences of different right-based organisations. Later sections address the application of human rights in programmes and organisations - practical ideas for education and HIV/AIDS programming; and four examples of rights-based programmes.

- **Human Rights Watch (2003). “Policy Paralysis: A Call for Action on HIV/AIDS-Related Human Rights Abuses Against Women and Girls in Africa” (www.hrw.org/reports/2003/africa1203/)**

This publication documents the full range of human rights violations that increase women’s and girls’ HIV risk and contains detailed recommendations to governments on how to curb these abuses as a way of improving their HIV/AIDS response.

is not fulfilling its responsibilities. Seek the help of national and international NGOs in documenting human rights abuses and analysing these abuses against international legal standards. Inform the public when a particular politician or political party opposes important legislation or proposes detrimental laws or policies.

■■ An important way to promote the right to health is to advocate for a strong health-care infrastructure and access to comprehensive care, including integrated sexual and reproductive health services and HIV/AIDS services such as voluntary confidential counselling and testing, and HIV treatment, as called for in international guidelines. □

5. Healthy sexual maturation

At the start of puberty, girls and boys begin to develop more rapidly. Faster physical growth and development, ending a few years later by physically being an adult, is accompanied by a dramatic social and psychological change. On average, this process starts earlier in girls than in boys.

During these years, adolescents (10–19 years) and youth (15–24 years) often test their boundaries and experiment with “being” an adult. The testing of different habits or lifestyles gradually leads to choices of interests, partnerhood and care development. Testing may be a mixed experience: feeling confused and inferior one day, while strong and assertive another.

During these years of experimenting, one tangible bodily change clearly is about sexuality. The hormones that spark off the acceleration of body growth are the same ones that initiate the sexual maturation. The bodily clock has started!

A major problem is for young people to obtain access to correct information on what is happening to them during these critical years. Many will either lack reliable information on issues such as menstruation, sexuality, pregnancy, contraceptives and masturbation or be swamped by incorrect advice, beliefs and suggestions. This painful lack of good information is often compounded by a lack of health services that could have helped to provide counselling and services on e.g. contraceptives, pregnancy and sexually transmitted infections. Additionally, sexuality is a taboo subject in most cultures, even in formal environments such as health services, while in the media it is often presented in a detrimental way. As a result, many young people simply have no one to turn to for information.

One particular challenge is the gender imbalance that is present in almost all societies, to which children and young people are socialised. Boys and girls will have grown up with views on the responsibilities and rights of the two sexes, and these attitudes will at this age be supplemented by beliefs in gender roles in sexuality. Gender discrimination and sexual abuse in a society risk being perpetuated if young people are exposed to them, directly or indirectly. Conversely, learning about the rights of other people and how they should be respected and treated, attracts much interest among young people if well introduced – especially the expectations and wishes of the other sex!

Introducing discussions on such topics is best labelled “life skills education” or “family life education”. It is really about life skills, how to treat other people, problem solving and interacting in a family – and not solely about sex. Part of this education should address the effect of globalisation on youth culture and consequently their behaviour. The internet, for example, is one purveyor of information that can be both helpful and harmful.

For all aspects of change in the boy and girl during these important years, environment, including socio-economic conditions, will be important. Typically, the role of family, friends, school and leisure activities is emphasised. Young people are quite sensitive to influences from these four fields in the shaping of their adult lifestyle and choices.

■■■ Entry points for NGOs

■■ Families: The role of parents is central. Most cultures traditionally have some kind of way of introducing young people to the facts of adulthood. In many cultures, the extended family has a large role in this informal “family life education”. Grandparents, aunts or uncles can, for instance, be in charge of teaching young people the basics of partnerships and sexuality. One of the problems of rapid urbanisation may be that close contact with older relatives is lost. Such intimate issues are often not so easy to discuss with one’s parents, as they may feel “too close”.

Examples of interventions: Parental meetings at school and in the neighbourhood, with both an educational and interaction/support goal. Special social efforts for single parents and for children that have lost one or both parents.

■■ Friends: Being part of a group of friends is very important

Box 8. Peer education and young people

A "peer" refers to a person who belongs to the same social group as others based on age, sex, sexual orientation, occupation, socio-economic and/or health status. And while peer education is often thought of in terms of young people in school, it is also relevant for miners, truck drivers, community members and so on. More on the theory of peer education in general can be found at: **www.popcouncil.org/pdfs/peer_ed.pdf**

for most adolescents, and where and how young people get together – in e.g. sports, clubs, or on the street – has an effect on individuals and the group. "Positive" ways for young people to meet, the healthy activities they should engage in, become extra important among unemployed youths. Peer education programmes, where trendsetting young people are trained and then "educate" their friends, is one important way of helping young people live a life that is safer from HIV (see Box 8).

Examples of interventions: Organised out-of-school activities for young people: sports, youth groups and clubs in which the HIV component can be explicit, implicit or not planned at all. Peer education on life skills including HIV. Support for youth activities via religious organisations where relevant.

■■ **School:** The issue of whether to go to school at all is a major factor that influences sexual maturation. This is especially important for girls. Going to school has direct effects on autonomy, self-esteem (which impact on the risk of early sexual debut), unwanted pregnancy and early childbearing. In addition to the factor of schooling in general is the civic education and life skills education that takes place at school.

Examples of interventions: Keeping young people in school and ensuring that going to school is safe, also from sexual abuse by teachers. Culturally sensitive, age-specific, factually correct information and life skills training for both boys and girls. The UNESCO/UNICEF/WHO/World Bank initiative "Focusing resources on effective school health interventions" (FRESH) summarises a few simple and effective interventions (available at any of their websites).

■■ **Leisure activities:** The existence of civil society groups where young people can engage is very important for the shaping of adult identity in all fields. The role of religious groups is potentially important, as they may have helpful options as regards young people's maturation. Clubs, sports, income-generating activities and safe and accepted places for young people to meet all play a role. One particular field is if and how young people can gain access to reliable information on sexuality. This is highly relevant as many young people are exposed to biased and discriminatory information (e.g. most pornography).

Examples of interventions: Safe meeting places, where young people can plan their own healthy activities (e.g. games, computers, homework from school) with adult supervision. Income-generating activities are another example that is also very relevant for young people living in resource-poor settings. Activities that increase voluntary access to correct information on sexual matters are also very much needed.

In all of the above perspectives, it is worth noting that sexuality is just one part (though an important part) of the daily life and formation of values that we call maturation. The entire context in which young people grow up plays a role in how they will handle responsibility, make choices, have self-esteem and treat other people including those of the same age and of the opposite sex. Will boys coerce girls into sex or show respect? Will girls have enough integrity and self-esteem to say no to sexual relations they do not want?

Any regular activity that supports any of the four key environments above has the potential to impact on healthy sexual maturation. If an NGO can act in several of the environments, important synergies are likely to emerge.

Resources

- **WHO (2003). Towards adulthood - Exploring the sexual and reproductive health of adolescents in South Asia. Geneva (www.who.int/reproductive-health/publications/towards_adulthood/)**

This book provides a comprehensive overview of the socio-demographic and sexual and reproductive health situation of adolescents in South Asia, including available evidence about health risks and challenges faced by young people. However, it also addresses issues not specific to Asia, such as factors that undermine adolescents' ability to make informed sexual and reproductive choices; the social context and health consequences of early marriage and childbearing; the sexual behaviour and attitudes of adolescents before marriage; sexual coercion; abortion, unwanted pregnancy and STIs; the physiological, behavioural and social risk factors surrounding STIs/HIV; and communication between adolescents and adults.

Box 9. Counteracting negative messages and promoting dialogue with young people: the Nyeri Youth Health project in Kenya

This project, planned by the Kenyan Family Planning Association together with the Nyeri community, first explored the beliefs of adults/parents, young people and community leaders on who should provide information to young people. The general opinion was that this should be done by adults, not by peers. Selected, respected young parents were therefore given one month of training in community, family and individual values; sexuality; gender roles; relationships; pregnancy; STIs including HIV, harmful practices such as female genital cutting, substance abuse, children's rights, advocacy and planning for the future. As counsellors, known as "Friends of Youth", they then counselled young people, and when the need for health services arose, they gave them coupons to cover the cost.

After the project had run for two years, adolescents and youth in the intervention area were much more likely to discuss issues of sexuality with adults and to protect themselves better against HIV infection and unwanted pregnancy, as compared to a control area. The Nyeri project is in particular outstanding because it was developed with the full participation of the local community and was designed to build on perceptions drawn from local culture and traditions.

For further reading: Erulkar AS *et al* (2004). "Behaviour change evaluation of a culturally consistent reproductive health program for young Kenyans". International Family Planning Perspectives 30(2):58-67 **(www.agi-usa.org/journals/ifpp_archive.html)**

- **Marston C (March 2002). Annotated bibliography of young people's sexual and reproductive health, Geneva, WHO. (www.who.int/reproductivehealth/adolescent/annotated_bibliography/)**

This bibliography is an extremely comprehensive guide to relevant literature on young people's sexual and reproductive health in less developed countries. The selection of papers is particularly focused on the following topics: young people's sexual behaviour, sexual coercion, dual protection, sexual/reproductive health seeking behaviour, abortion, laws and policies affecting youths' sexual and reproductive health, operations research and

Other areas for NGO action

Legal: Raising the age of marriage and first birth for girls contributes to the improvement of their decision-making power and improved sexual and reproductive health. While the age of marriage can be changed by legal means, education, the financial situation and health care are all areas where NGOs can play a role. For example, by supporting income-generating opportunities for girls, they may delay their first birth;

Sex education: Use local risk perceptions as an entry point for HIV education and use locally available media, e.g. the radio or newspaper. If, for example, young women are more concerned evaluation of interventions, quality of care/provider perspectives, and special needs of migrant and refugee youths.

- **CEDPA. Adolescent Sexual and Reproductive Health: A Training Manual for Program Managers (www.cedpa.org/publications/pdf/catalyst_adolescent manual_english.pdf)**

This training manual is directed to coordinators of youth programmes. The manual sets out to build the capacity of professionals in managerial positions to better equip them to identify and design programmes that respond to the adolescent sexual and reproductive health and rights of young people. Users will explore and develop various strategies and interventions at the national, local, organisational, community, family and individual levels. This 224-page manual covers four main issues: gender, human rights, youth/adult partnerships and sustainability.

- **UNESCO. International Clearinghouse on Curriculum for HIV/AIDS education (http://portal.unesco.org/education)**

This website is a goldmine of curricula and syllabi for life skills education focusing on HIV/AIDS. It gives full details on the tools of numerous educational programmes for young people, for different settings and ages, and provides links to them to evaluate how relevant the material is for your projects. One of the most important of them is the Focusing Resources on Effective School Health (FRESH) initiative, which provides a basic framework for comprehensive school health programming. Another is the "Resource Package for School Health Education to Prevent AIDS and STD", which includes a handbook for curriculum planners, a teacher's guide and a student activities book. The latter is chock full of activities on basic HIV/AIDS/STI knowledge, responsible behaviour (e.g. delaying sex and protected sex) and care and support.

- **Magnus Hirschfeld Archive for Sexology, Humboldt University in Germany (2005). E-Learning Courses in Sexual Health (www2.hu-berlin.de/sexology/)**

In addition to a critical dictionary addressing sexology, this site hosts free online courses addressing human reproduction, sexually transmitted diseases and sexual dysfunctions.

about unwanted pregnancies, use that as the point of departure for dialogue and education about HIV/AIDS prevention;

Violence: Ensure that special attention is devoted to the risk of partner violence and other abuses that young women might be victim of when they disclose that they have taken an HIV test. Studies show that some men may interpret their partner's taking an HIV test as an attack on their fidelity or as an indication of the woman's unfaithfulness;

Youth-friendly health services: increase the general youth friendliness of existing health services. Increase access to counselling and provision of reproductive health services for boys and girls by promoting these activities in existing health services and new venues;

Special counselling for young married women: Offer tailor-made counselling to young married women through existing family planning services;

Prevention in family planning and reproductive health settings, voluntary confidential counselling and testing, maternal and post-abortion services are discussed in chapters 13,14,15 and 17. □

6. Sexual minorities and same-sex sexual activity

People have different sexual preferences. This is true on different scales, such as "if to have sex at all", "when, where and with whom to have sex", "how often" and "if there is a desire to protect against pregnancy or not", i.e. to use contraception.

When it comes to details surrounding the sexual act, people also have different preferences: on how to become sexually aroused, how to please the partner, positioning during the sexual encounter, sexual variations with the partner and so on. These are often very intimate issues that are not discussed with anyone, and perhaps not even with the sexual partner. Why people have different sexual preferences is difficult to say. However, one can simplify the matter by saying that we have varied sexual preferences just as we have different preferences in other areas, and that these reflect our wide-ranging personalities.

It is also important to understand that sexual activity is not always coherent. It is not unusual that same-sex sexual activity is a choice for individuals for different reasons and in different situations. This is a fact for both men and women. For some, same-sex activity is not considered to be sex, as understood in that specific cultural context. In HIV prevention the phrase "men who have sex with men" (MSM) has been created to include a phenomenon with risk exposure to HIV. This phenomenon is important to take into consideration when planning prevention interventions. Potentially, MSM can be a transmitter of HIV or other STIs between different groups in a specific population if they also have sex with a woman, i.e. they may be bisexual. The equivalent term for sex between women is "women who have sex with women", (WSW). However, due to differences in sexual techniques, sexual activities between women are less risky as regards HIV transmission than sex between men, or sex between a man and woman.

Homosexuality

Some people relate emotionally and sexually with persons of their own sex, hence the term homosexual. Having homosexual preferences occurs in all cultures and countries. The difference is in how cultures and societies have perceived and looked upon this group. Many people with homosexual preferences gradually become aware of these during adolescence and early adulthood. For some, it is realised later in adult life. They will often initially perceive themselves as being different from others, and sometimes wonder "what is wrong with them" because they do not, like their peers, feel an interest in the opposite sex. After a period, sometimes years of searching and experimenting, homosexual women and men eventually come to realise their main sexual preference, and this usually comes as a great relief.

Often, this occurs in connection with falling in love with a person of the same sex, and acknowledging and accepting this intense feeling. It is also at this time important to understand that having homosexual preferences is not uncommon, that it actually is a rather common occurrence among human beings.

Reaching this personal maturity is not easy in an environment that attempts to repress homosexuality. In some countries, homosexuality is illegal and can even lead to imprisonment. It is hard to imagine the misery of a homosexual person, realising that the way one has evolved as a person, the way one experiences attraction and love, is considered criminal.

There may be a number of reasons given for the penalisation of homosexuality. It can by authorities be perceived as "western decadence", but in many cases it is a Victorian heritage, and many countries that were colonised have not sufficiently thought through their inherited laws and the consequences of them. Or it may be referred to as an anomaly. The latter is not true, however, since research shows that sexual activity between people of the same sex exists in all cultures. Whatever the reasons for criminalisation and penalisation of homosexuality, and the ensuing discrimination of homosexuals, they reflect a lack of understanding of the background of homosexuality, of the misery of homosexuals persecuted in this way, and of the human rights abuse that such policies reflect. Also, they tend to accelerate the HIV/AIDS pandemic by driving homosexuals and homosexual practices underground – where they are more difficult to reach and protect.

Some religious faiths condemn homosexuality and/or homosexual practices. Such religious groups show the same lack of insight and human respect as governments that punish homosexuality. Faith-based organisations have a potentially very large role in promoting human rights, also for these groups.

A forced act between people of the same sex is not a major feature of homosexuality, nor is “seduction” into homosexuality. Sexual acts in some same-sex environments, like between men in prisons, is usually not a true reflection of homosexuality and is better referred to as MSM; and seduction into homosexuality is not possible, as it is not possible the other way around either. People can sometimes, for different reasons, perform sexual acts against their own inner conviction and feelings, but there is a clear distinction between sexual acts and sexuality. The latter is more closely related to one’s personal identity, be they heterosexual or homosexual.

In countries where discrimination and systematic misunderstanding of homosexuality is commonplace, homophobia, the fear of homosexuality, is also often widespread.

Acknowledging the simple fact that some people have a homosexual orientation, respecting this and supporting policies and laws that take this into account will go a very long way in not only defending the human rights of this group of people, but also in helping them in protecting themselves and their partners against HIV. They have the right to a safe sexual life in the same way as anybody else.

Bisexuality

While many people, apart from their main sexual orientation, occasionally have sexual impulses towards the other sex, some will actually be bisexual, and threrefore have both a strong homosexual and heterosexual orientation at the same time. It is probably relatively rare that the two sides are of equal dimensions. Usually, one orientation is stronger.

A more common form of bisexual practice among men or women is to live in a heterosexual relationship and hav homosexual encounters outside of this relationship. This often reflects a homosexual preference that has either become clear to the person later in life, after marriage and parenthood have taken place, or an adaptation to a homophobic environment. This may also be a person referred to as MSM or WSW. Such practices can significantly increase the risks of HIV transmission as information or peer programmes for homosexuals often do not reach the person.

While responsible and explicit bisexual orientation and practices among mutually informed and consenting adults, practising safer sex, can be an expression of care, love and intimacy, clandestine bisexual practices involving minors or exploiting partners is another matter altogether.

Transgender

In recent years, “gay, lesbian, bisexuality and transgender” (GLBT) have been increasingly mentioned in one context. This serves to underline the fact that sexuality has many different expressions and variations, beyond heterosexuality (and beyond GLBT, too).

Transgender is a composite of two different dimensions of gender and expressions thereof. Firstly, transsexuality means that the inner perception the person feels of oneself psychologically is actually that of being of the opposite sex. In this case, women or men feel that their body does not reflect their psychological gender identity. A man feels that his correct gender is female, and vice versa. After appropriate counselling, and when available,

Resources

- **Niang CI et al (2002). Meeting the Sexual Health Needs of Men Who Have Sex With Men in Senegal (www.popcouncil.org/pdfs/horizons/msmsenegal.pdf)**

Research conducted in many countries has highlighted the vulnerability of men who have sex with men to HIV and other STIs. Yet in Africa, they receive little attention in HIV/AIDS programming and service delivery because of widespread denial and stigmatisation of homosexual behaviour. In Senegal, a study conducted by researchers from the National AIDS Control Program (PNLS), Cheikh Anta Diop University and the Horizons Program has provided valuable information about the needs, behaviours, knowledge and attitudes of MSM that has important implications for programme managers and policy-makers working to stem the spread of HIV/AIDS.

- **UNAIDS (1998, updated in 2000). “AIDS and Men who Have Sex**

some of these individuals will by hormonal and surgical means correct their sex.

Transvestism is the other dimension. This means that a person feels an inner satisfaction when bearing clothes or other attributes that are usually worn or used by persons of the opposite sex. This should not be confused with the transvestism sometimes occurring in shows, as entertainment. Nor should it be confused with transsexuality. Transvestites can have either a heterosexual, bisexual or homosexual orientation. In fact, most transvestites are heterosexual.

Interlinkages among the sexualities

Of the sexual minorities presented above, homosexuality is by far the most common. As indicated, a number of other sexual preferences and variations exist, other than the ones mentioned. They have the following in common:

1. Sexual practices and personal expressions that are non-exploitative and involve mutually informed, consenting adults practising safer sex without harm to themselves or others should be respected and accepted, and not criminalised.
2. Sexual activities do not have to be coherent with sexual identities as they are perceived by the persons themselves or how they are looked upon by others. Same-sex sexual activities are common both among men and women.
3. As different sexual practices – when unprotected – carry different risk levels of HIV transmission, appropriate measures need to be taken to make different practices safer. The only way of achieving this is by involving the individuals themselves in the design of informational material and peer group information efforts.
4. The above efforts should be based on the scientific knowledge available for the different practices and the protective measure known for each of them.

Interventions

Sexual practices that carry a high risk of HIV transmission can be made safer by modification, taking up “safer sex”. This requires knowledge of current practices, awareness of HIV/AIDS and good communication skills. These ingredients are best found in peer education programmes where key persons, themselves practising sex in non-conventional ways, are trained to act as educators, transmitting new knowledge, attitudes and skills to their peers. There is much evidence that peer education programmes for high risk groups, including sexual minorities such as homosexuals and men who have sex with men, is a cost-effective intervention to reduce HIV spread.

Persons of minority groups who have risky behaviour, and have possibly been driven underground for legal reasons, are often

with Men." Best Practices: Point of View. Geneva, UNAIDS.
These documents provide a technical summary of the issues, challenges and solutions; case studies from around the world; a set of presentation graphics; and a listing of key materials (e.g. reports, articles, books, audiovisuals) on the subject.

- **Advocates for Youth (2003). "GLBTQ Youth: At Risk and Underserved" and "Adolescent Sexual Health and the Dynamics of Oppression: A Call for Cultural Competency" (www.advocatesforyouth.org/publications)**

The first paper is a fact sheet that spells out the problems gay, lesbian, bisexual, transgender and questioning (GLBTQ) youth face in a heterosexual society. The second paper provides three-steps encouraging those who work with youth to understand the impact of prejudice and discrimination on vulnerable adolescents, to assess and address their needs, and to build on their assets.

a strong driving force in implementing peer programmes once they recognise the increased risks they themselves are facing, and once they receive adequate support. Peer programmes for high risk groups are cost-effective both in the beginning of the HIV epidemic in a country and in later stages of a national epidemic, when HIV is widespread in the general population. When designing interventions one has to consider the general knowledge in the target population when it comes to sexual anatomy and physiology. One can not presume that all have a basic scientific knowledge, which is essential for a wider understanding of sexuality and its variations, as well as an understanding of HIV and its prevention.

■■■ Entry points for NGOs

■■ One of the most important things NGOs can do is recognise and address the existence of different sexualities in all of the target groups they address in their own work. This requires that they differentiate activities, e.g. counselling sessions and informational material, in order to ensure that they encompass sexual minorities and that, where relevant, they specifically target these minority groups.

■■ By also targeting heterosexual audiences with information about sexual minorities, stigma may be reduced. This can be done by including safer-sex advice about such activities in material directed to the general population. However, this should be done only after pilot testing the material as it may be fully rejected by the authorities or certain groups in the general population if it includes such information.

■■ Policy-makers should be lobbied to ensure that laws which discriminate against sexual minorities, e.g. prosecuting homosexuality, are changed.

■■ NGOs should support existing associations and other organisations made up of or which work with sexual minorities and help establish them where they do not exist.

■■ Identify sexual minorities in a country, and in contact with key people in such subgroups support the development of partly self-run peer education programs. □

7. Discrimination, coercion and violence

Gender-based imbalance in power has been mentioned in Chapter 1 as a factor that contributes greatly to the HIV pandemic. The fact that women on average have much less of a possibility to control when, how and if safer sex is practised than men is a contributing factor to this. Other related aspects are the discrimination, coercion and violence against women that occur to varying degrees in all societies. Although women and girls are more often the subject of violence than men, boys and young men can also be victims of violence and abuse by women or other men. This can be particularly traumatising as it is often followed by a double stigma since gender-based violence against men is an even more taboo issue than when it concerns women.

Discrimination against women encompasses a set of restrictions hindering women from playing a part in society that is equal to that of men. Such discrimination usually starts during childhood, when girls and boys are socialised to the traditions and perceptions of gender that are common in that particular society. It is important to note that this socialisation process normally is propagated by both men and women in a society. Expressions of discrimination against the girl child – as compared to boys in the same society – are increased malnutrition, hard labour, neglect, inappropriate health-care seeking behaviour and often violence. In a few countries in Asia, the combined result of such discrimination is the "missing women" – at, for example, ages 15–20, up to 10% of girls/women are literally missing. They have succumbed due to sex-selective abortions, female infanticide and neglect and malnutrition during childhood. Fortunately, such stark aggression – leading to several hundred thousand women missing – is localised to only a few countries and usually specific regions in these. Widow burnings and honour killings are, however, similar reflections of structural violence.

A very common expression of discrimination of girls is their inability to go to school, or that they get less schooling than boys, on average. One of the quickest ways to get a rough assessment of the degree of gender-based discrimination in a society is therefore to compare literacy among girls/women to that among boys/men. According to UNESCO, in developed countries overall, literacy rates are the same for young men and women. But in sub-Saharan Africa, only 81% of male youth are literate and 72% of female youth. Conversely, ensuring schooling for girls is one of the best interventions to enhance development in low and middle income countries overall. One could say that few countries "can afford" not to exploit the full capacity of women. Regarding schooling, it has been shown in a number of countries that keeping girls in school delays age of sexual debut, marriage and first birth. The reasons behind this are several, but they include "empowering" and increasing the self-esteem of women, and the relative increase in value of women as seen from the family's perspective.

Sexual coercion

Sexual coercion of girls and women is a common phenomenon. It can be defined as forced or involuntary/non-consensual sex, and exists in many varying degrees and forms, from persuasion to violent and systematic rape. Contributing factors, apart from gender discrimination in general, are the traditional (sexual) submissiveness common in some cultures – girls are brought up to not say no – and poverty. In some countries of sub-Saharan Africa transgenerational sex is quite common. The system of "sugar-daddies", in which older men attracting girls initially with "gifts", later becoming their "protectors" in exchange for sexual services, is widely prevalent, and a high proportion of, for example, female university students rely on such relationships. Coercion is also a problem among schoolteachers who abuse children sexually, college and university teachers who demand sexual services to certify successful exam results, and policemen who use their power for sexual abuse.

Young girls are often at higher risk, either because they are considered HIV free, or because of the belief that having sex with a virgin will cure the perpetrator from HIV. It is more rare that men, knowing themselves to be HIV positive, express their rage by trying to infect as many partners as possible. Good counselling in connection with HIV testing and adequate support of HIV-infected individuals go a long way in preventing such reactions. In a number of wars and conflicts in recent years, systematic rape has been one part of one society's aggression towards another, and as such a component of "ethnic cleansing". More information about this can be found in the Chapter 10 on emergency situations.

It is estimated that as many as one woman in five has been sexually abused, or coerced into sex, during their lifetimes. This also happens within marriage. Clearly, sexual coercion increases the risk of transmitting HIV. The woman has little or no negotiating power and cannot deny sex nor demand safer sex practices such as condom use. Abusive men are more likely to be HIV infected because they also practise other forms of high risk practices. Sexual abuse and coercion also increases the risk of transmission of other sexually transmitted infections, and unwanted pregnancy, with the potential result of either unsafe abortion or unsafe birth.

Sexual coercion of boys and small children is not uncommon in some societies and this carries many risks: physical and psychological damage, and HIV infection. Psychologically, such brutal behaviour towards boys and girls may contribute to mental ill-health and create tomorrow's sexual perpetrators. Children witnessing adult domestic violence, most commonly intimate partner violence against women, have been shown to have increased violent behaviour, more likely among boys than girls, as they grow up. The perpetration of a societal cycle of violence is also enhanced by civil strife/violence in society/war, extreme poverty and the widespread use of alcohol.

Violence

Violence against women also has many other forms than sexual coercion and abuse. Men's violence against their intimate female partners – the most common form of gender-based violence – is rarely an isolated phenomenon but rather one expression of male control over a wife/fiancée or similar. Other common expressions include psychological and verbal abuse, prohibition of social contacts, education, work and contraception. Alcohol and drug abuse are often associated factors as well as violent problem-solving behaviour in society. It is also striking how men's violence against women is widely prevalent in both low, middle and high-income countries. It is truly a global public health and human rights challenge to be fought wherever it exists. The psychological effects of partner abuse and sexual coercion are numerous: lowered self-esteem and personal autonomy, self-destructive behaviour (e.g. alcohol and drug abuse, prostitution, suicide attempts/suicide), mental ill health (e.g. depression, post traumatic stress disorder) and violent behaviour (e.g. abuse of own children).

In a poor society, the vulnerable position of many individuals exposes them to a heightened risk of abuse through the misuse of power, through corruption and lack of law enforcement.

Interventions

During the last ten years, awareness has increased among the public and among decision-makers about the challenge of violence and sexual coercion against women, and sometimes against children. In many countries, interventions have started up, e.g. stronger legislation and enforcement (Nicaragua), police stations staffed only by women (Brazil) and school health programmes that address student safety ("FRESH"). Much of the spearheading of such work is being done by NGOs, often in national networks. Much more needs to be done in this area – redressing laws or integrating identification and care for abused women into sexual and reproductive health services – to make

Resources

- **WHO (2002). World Violence Report (www.who.int/violence_injury_prevention/violence/world_report)**

This is the first comprehensive review of the problem of violence on a global scale – what it is, whom it affects and what can be done about it. This report examines the types of violence that are present worldwide, in the everyday lives of people and that constitute the bulk of the health burden imposed by violence.

- **PAHO (2003). Violence against Women: The Health Sector Responds (www.paho.org/English/DPM/GPP/GH/VAWhealthsector.htm)**

This book provides a strategy for addressing gender-based violence and concrete approaches for carrying it out, not only for those on the frontlines attending to the women who live with violence, but also for the decision-makers. Drawing on examples from Latin America, this work addresses issues like why violence is invisible in the health sector and where policies do exist, how they work.

the life of girls, boys and women free from sexual aggression and violence. Leading men in society have a major role in raising the issue of violence as a public health threat in general, and as a propagator of HIV in particular.

■■■ Entry points for NGOs

- Support interventions that contribute towards gender equality: microcredit schemes for women to start small businesses or farms; improved legislation that permits all women to vote; inheritance and land ownership rights; and schooling for girls and women;

- Support local or national NGOs and NGO networks that focus on the issue of violence against women (such as “safe houses”, policy work, manifestations);

- Vocalise the unacceptability of violence against women, including sexual violence and coercion;

- Support changing of legislation, including the penalization of rape, also within marriage;

- Engage men in public awareness raising regarding (sexual) violence against women, girls and boys in society;

- Where the above issues are “hushed down” support action-oriented research that helps to expose the situation and widely publicise the results of such commissioned studies;

- Lobby for free antiretroviral treatment for women that have been raped as well as the widespread availability of post-exposure prophylaxis kits;

- Help organise centres for women that have been raped. Social and legal support as well as health care should be provided here. Health care should include both emergency contraception and post-exposure prophylaxis against HIV;

- Lobby for permission to go back to school for school-age girls that have given birth;

- Be aware that boys and young men might also be victims of gender-based violence;

- Support all advocacy and legal activities that highlight the responsibility of male perpetrators and not the female victim;

■ **Jejeebhoy SJ and Bott S, Population Council/India (2003). Non-consensual Sexual Experiences of Young People: A Review of the Evidence from Developing Countries (www.popcouncil.org/pdfs/wp/seasia/seawp16.pdf)**

This 42-page paper synthesises the available information on non-consensual sex of youth in developing countries, the research on the nature and extent of coercion, adverse consequences and underlying risk factors. It also includes recommendations for programmatic and research priorities. Non-consensual sex was found to cover a continuum of behaviours ranging from unwanted verbal advances to unwanted touch to assault and forced sex, as well as sex in exchange for money, gifts, food or protection. It occurs largely among individuals who are acquainted with each other. The review concludes that non-consensual sex is experienced largely by girls and women, but also by boys and men. There is also evidence that it is commonplace among married couples.

■■ Ensure that VCCT centres are aware of the risk of violence that their female clients might be subject to. ☐

8. Orphans and other vulnerable children

Children, defined as individuals below the age of 18, in low-income countries are growing up in societies where they are prone to be exposed to deficient educational, health and other social service systems. Yet in many such societies, the extended family is considered to be the basic social unit where children find affection, physical comfort, support, food and other resources, protection against harm and joint problem solving. NGOs and other civil society organisations, with their close contact with local communities, have a special role to play in the protection of the rights of children, some of which are listed in Chapter 4.

The current HIV/AIDS situation, armed civil conflicts, migration from rural to urban areas, changing marital practices, rising costs of living and enduring economic decline have posed severe strains on family networks for the caretaking of children. In some African societies, poverty has led to alterations in cultural values of children. While previously perceived as blessings, children have become economic burdens for many families. These changes have made some children particularly vulnerable and susceptible, especially to the threat of HIV infection and sexual abuse.

To be vulnerable means to be in a social situation where one does not receive appropriate care, resources or recognition. Thus an individual as such is not vulnerable, it is the social situation of that person which makes him or her vulnerable. If that social situation is further embedded in an environment of AIDS, the individual becomes both vulnerable and susceptible. Children are the most exposed victims of such a scenario. Due to AIDS in the family, children may quit school altogether: the boys may be taken out of school in order to earn money for the survival of the family, while the young girls may have to provide care for sick parents. Girl orphans might continue with the role of care provision for siblings even after parental death, which might lead to sexual exploitation and the risk of becoming HIV infected. Such young girls may develop AIDS during their teenage years, which can compromise their chances of fulfilling the cultural norms of entering into marriage and motherhood. In addition, the stigma of living with AIDS may put these youngsters at risk of receiving less social security and care.

Box 10. Strained kinship relationships and the shared vulnerability of Samia widows and orphans in Uganda

Abalekwa, "the people who have lost" or "the people left behind". This local term in Uganda traditionally includes widows/widowers and their offspring. The linkage between the parent and children reveals an interdependence as well as a recognition that children always belong to somebody – a family, a piece of land and a clan. Most people know a child through relations with the mother or father, and it is because of their relations with the parent(s) that they will (or will not) care for the children. A child is never just an orphan but rather "my sister's child", for example.

Emma is a 20-year-old girl whose father died of AIDS in 1997. Her parents had been on such bad terms that in 1994 her mother left home and ultimately managed to establish a small business. Soon afterwards, she picked up the children, only to return a year later to care for her then dying husband. When he died, the in-laws chased the woman and her children off the land, refusing any compensation or future assistance. According to the father in-law, Emma's mother had "gone outside" the marital relationship and introduced AIDS to the family, which had claimed her husband's life. Blaming her for what happened, they did not want to live with a "murderer" or her children.

In societies where inheritance customs grant a man's land and property to his closest male relatives upon his death, accusations of causing AIDS, lack of morals and having caused death may be the extra factor leading widows and their children to be forced off their land.

In any society affected by HIV/AIDS the most common problem is when children become vulnerable as their parents die of AIDS: they lose their primary caregiver. Many projects have tried to assist orphans (children below 18 who have lost one or both parents) by establishing "orphanages". However, UNICEF has in the Children on the Brink report (2004), stated that orphans preferably should not be singled out, as this often works as a double stigmatisation. Instead, assistance should be given to the communities where HIV/AIDS is making children and adolescents the most vulnerable age group.

Aside from the influence of social and cultural values, other features of a child's social situation must be included in assessments of vulnerability, especially the child's age and sex. Furthermore, the available resources of other people within their social network and their willingness to actually perform the caretaking are crucial. The latter issue of willingness to care-take is often downplayed to a matter of economics. However, this may just be one side of the coin. Accusations between spouses and between relatives as to who introduced the disease to the family may lead to severe neglect and punishment of the children left behind, particularly in societies heavily affected by HIV/AIDS. The examples in boxes 10 and 11 address these two points: strained kinship relations rather than economics may put the children at risk and children may be understood as symbols of adult relations rather than individual persons.

Another way that children are affected by the epidemic is that in hard hit communities, children might be the only caregivers around to take care of their parents or other elders. For children to take care of their own parents and possibly also see them die is a traumatising experience which children need help to deal with. As Save the Children Denmark states about children in North Wollo in Ethiopia (see Box 11): "...children watch their parents dying without knowing the nature of the illness and no preparations are made for their future. Relatives or neighbours disclose the nature of the sickness often in a discriminatory manner causing considerable psychological stress on children". Furthermore, due to poverty, orphans as well as children are often forced to leave school and seek employment opportunities. Recently, the International Labour Organization documented how work increases the vulnerability of children to HIV/AIDS as child workers are often separated from their families and are more susceptible to sexual abuse and exploitation as well as drug and alcohol use.

Box 11. Advocating for children's rights in North Wollo, Ethiopia

Since 1998, Save the Children Denmark has been working with an integrated child development programme, which includes awareness about HIV/AIDS, children's rights and access to basic education. In 2001, a study in North Wollo regarding the HIV/AIDS situation and its impact on child rights was carried out. One of the main findings was that there was a lack of knowledge of and respect for child rights and a low level of awareness about HIV/AIDS. As an attempt to try to change this situation, Save the Children designed the "Child Rights focused HIV/AIDS Project for Children and Youth in North Wollo". The project tries to create awareness about HIV/AIDS and the Convention on the Rights of the Child through a range of channels and activities, including the media, children's clubs, trained peer educators and teachers. Additionally, a range of various advocacy and training events have been planned and carried out for key gatekeepers, such as select community members and HIV/AIDS councils.

Source: Save the Children Denmark: Child Rights focused HIV/AIDS Project for Children and Youth in North Wollo, Ethiopia (Project document).

Resources

- **A Parrot on your shoulder – a guide for people starting to work with orphans and vulnerable children (www.aidsalliance.org/eng/publications/_prom/parrot.htm)**

This resource, developed by the International HIV/AIDS Alliance, encourages participation in practice. It seeks to support individuals and organisations working with orphans and other vulnerable children living in a world with HIV/AIDS. This fully illustrated activity guide provides advice on children's participation, as well 30 detailed examples for activities aimed at engaging children actively in discussions.

- **Red Cross (2002). Orphans and other children made vulnerable by HIV/AIDS: principles and operational guidelines for programming (www.ifrc.org/what/health/tools/orphans.asp)**

This document from the International Federation of Red Cross and Red Crescent Societies provides guidelines for those helping communities and families to strengthen their traditional coping mechanisms and meet the challenge of addressing the needs of orphans and other children made vulnerable by HIV/AIDS.

- **Kilbride P, Suda C and Njeru E (2000). Street Children in Kenya. Voices of Children in Search of a Childhood**

This book addresses "street children" as children living "in" or "off' the street. Based on comprehensive studies in Nairobi, Kenya, the authors describe the temporality of children's lives "in" the streets and the family push-factors of children living "off" the street. The book discusses the recurring features of street children's lives everywhere regardless of the country they are in and includes suggestions on how to improve the lives of these children through the involvement of extended family networks.

- **Save the Children, UK (2004). Yousafzy A and Edwards K. Double Burden. A situational analysis of HIV/AIDS and young people with disabilities in Rwanda and Uganda (www.savethechildren.org.uk)**

The purpose of this situational analysis was to explore the knowledge of HIV transmission and prevention among young people in Rwanda and Uganda and to look at the determining

Entry points for NGOs

- Protect the family unit by helping the parents to avoid HIV infection (prevention) or to delay the onset of AIDS (e.g. by way of treatment of opportunistic infections and access to ARV drugs);

- Help orphans to remain in the community, possibly with relatives or a foster family, or a community run organisation when the former is not feasible;

- Safeguard their rights to protection, schooling and property, including the right to inheritance, property and land – which may be abused by distant relatives;

- Conduct vulnerability assessments to identify the social situations that are most likely to expose children to sexual abuse and other risk factors related to HIV infection;

- Promote children's right by advocating for the full implementation of the Convention on the Rights of the Child (see Chapter 4 on the rights-based approach). ☐

factors regarding their vulnerability to infection and/or inappropriate management of HIV/AIDS. It addresses the specific needs of young people with disabilities and provides further insights into vulnerable populations in the light of the HIV/AIDS pandemic.

- **International HIV/AIDS Alliance (2004). Building Blocks in Practice – Participatory tools to improve the development of care and support for orphans and vulnerable children (www.aidsalliance.org/eng/publications/_prom/buiding_blocks/building_blocks.htm)**

This publication contains tools on education, health and nutrition, psychosocial support, social inclusion, economic strengthening and supporting older carers. These are designed to support communities working in partnership with NGOs, community or faith-based organisations or with a trusted community member. They focus on different issues connected with improving the community care and support provided to orphans and other vulnerable children.

- **Christiansen, C (2003). Reflections on the Changing Patterns of Care for Orphans in: CODESRIA Bulletin, Special Issue 2, 3 & 4: 94-98 (http://www.codesria.org/Links/conferences/hiv_aids/christiansen.pdf)**

This paper provides a definition of the concept of care and reflections on the long-term influence of the patterns of care for orphans, amongst others the emerging institutional settings for childcare.

- **UNAIDS and UNICEF Children on the Brink 2004: A Joint Report on Orphan Estimates and Program Strategies (www.unicef.org/publications/index_22212.html)**

In addition to extensive data on orphans, useful when planning interventions, this report also presents five key strategies to assist children as well as 12 principles for planning. Among the useful resources presented at the end is a link to the Children Affected by AIDS Discussion Forum, one place NGOs can go to seek further information when developing projects addressing orphans and other vulnerable young people.

9. Protecting the vulnerable

The HIV/AIDS pandemic in all countries tends to hit certain vulnerable groups extra hard. These groups are often poor, powerless and have increased exposure to coerced sex and to intravenous drug use. They count among them handicapped people, homeless persons and prisoners.

NGOs have a particular role in helping to protect these groups, as they in many low and middle-income countries do not get sufficient attention from the public authorities. This may be simply because the country is poor, because the groups have little political influence, that one ascribes less human value to them or even that one actively tends to hide these “failures of society”. This is one aspect of the HIV/AIDS pandemic where there is much to do from a human rights perspective.

Vulnerable groups:

Orphans and other vulnerable children

Children who have lost one or both parents either to AIDS or due to some other incident or sickness are regarded as highly vulnerable to HIV, in part because these households are often characterised by extreme poverty. Due to this poverty, children may be forced out of school and into various forms of labour. Child workers are often separated from their families and are more susceptible to sexual abuse and exploitation as well as drug and alcohol use (see the previous chapter regarding orphans and vulnerable children).

Young people

Young people make up a particularly important group for a number of reasons: firstly, young people have sex – in most countries young people are sexually active before the age of 15. The earlier their age at sexual debut, the more at risk they are, as they are more likely to have sex with high-risk partners or multiple partners, and are less likely to use condoms. This is often due to the fact that young people lack information – many do not know how HIV/AIDS is transmitted or how to protect themselves – or lack access to contraception. Furthermore, misperceptions are widespread, particularly as young people primarily get their information from peers and the media.

The years of adolescence and youth are often also years of experimentation. Young people are exposed to drugs and more specifically to drug injection and skin-piercing. In some contexts traditional scarification can also increase the vulnerability of young people to infection (for more information about adolescents, see Chapter 12).

Men who have sex with men

In many societies, homosexuality and bisexuality are not accepted, with the result that men who have sex with men (MSM) are marginalised. Due to this marginalisation, MSM are often victims of intense stigmatisation and discrimination and face severe difficulties in accessing correct information and services related to their particular vulnerabilities with regard to STIs including HIV (For more information see Chapter 6 regarding sexual minorities).

Injecting drug users

Injecting drug users (IDUs) are vulnerable to HIV infection through contaminated syringes and needles. In order to prevent the virus from spreading, injection equipment needs to be either sterilised or new needles and syringes used. However, there are several barriers for IDUs to overcome to secure safe injection practices. Purchasing injection equipment is not easy due to the cost involved, unavailability of the injection equipment and the stigmatisation they encounter from the pharmacists selling the needles and syringes. Furthermore, it is often very risky for IDUs to carry needles and syringes, as illicit drug use is illegal in all countries, and IDUs often face punishment if found with injection equipment. Finally, IDUs put their sexual partner at risk of becoming infected if condoms are not used correctly and consistently.

Female sex workers

Due to their highly marginalised status in society, female sex workers (FSWs) have little access to accurate information about reproductive health and STIs including HIV. Cultural, economic and social constraints limit their access to legal protection and to medical services. The main strategy to prevent FSWs from becoming infected with HIV has so far been the promotion of condom use. However, FSWs often face problems when negotiating condom use with their clients, as some client's claim that condoms reduce sexual pleasure. For this reason, effort has been put into finding alternative contraceptive methods such as the female condom and, more recently, microbicides. These contraceptive methods may improve the FSWs' situation as they are in control of using them. Finally, it should be noted that FSWs often have a high prevalence of STIs. Therefore, the effective diagnosis and management of STIs is crucial in HIV prevention efforts addressing them.

Mobile populations

Many people, particularly in low-income countries, migrate from rural to urban areas in their search for jobs or education and economic prosperity. Others have jobs that require regular movement, e.g. truckers, traders, business people or members of the armed forces. A common trait of all these people is that they are away from their family and community, which many times leads to a drastic change in norms. As couples might be apart for many months at a time, extramarital relations sometimes develop and men may turn to FSWs to satisfy their sexual needs. In most countries it is men who migrate and leave the women and children behind. The fact that the main breadwinner leaves often puts women in a particularly vulnerable position as they have to cope with less financial and labour resources. In some cases this pushes women into prostitution and children out of school.

The handicapped

Many readers of this manual will not associate handicap, or physical or mental disability with increased exposure to HIV. In many less well off countries there will be little extra support for these people, and if they come from poor families – and people with some disabilities tend to intermarry, enhancing the poverty – they will be more exposed to the risks of exploitation and coercion. Powerlessness and discrimination may mean lack of power to defend oneself against sexual coercion, manipulation in the workplace (if there is one), at home and in the family. This raises the risks of lower self-esteem, malnutrition, illiteracy, poverty, infections including STIs and HIV – and little ability and few funds to seek help.

Renaming "the disabled" as "differently abled" steers thinking to a wider understanding of disability. The different abilities of many individuals will not be noted or not be important if the surrounding has been adapted to their situation. One can thus question if it is the person that is disabled, or society. With limited adaptation of the context, and impacted on by severe poverty and lack of understanding to the point of accusing the disabled of witchcraft or evil eye, it will be difficult to reverse the situation.

Physical handicap, including various types of sensory impairment (e.g. deafness or blindness), mental handicap including both mental deficiency and mental disease/disorder, and combined physical/mental handicaps are the main groups of disability. Many smaller groups or people suffering from locally prevalent problems (e.g. from leprosy, war injury or environmental disaster) can be encountered.

It is important to note that having AIDS has also been formally classified as being handicapped by WHO. This highlights the debilitating aspects of this disease and also further strengthens the links between disability and HIV/AIDS.

Resources

- **WHO, Médecins Sans Frontières, Penal Reform International and AIDS Foundation East West (2001). HIV in Prisons (www.euro.who.int/document/e77016.pdf)**

This book aims to pass on the most up-to-date and best knowledge and ethical standards in responding to HIV/AIDS in prison settings. It reviews the epidemiology of HIV/AIDS in prisons, human rights in prisons, high-risk behaviour, monitoring HIV infection, HIV/AIDS prevention and treatment, TB, STIs, women and protecting prison staff. It concludes with the WHO guidelines on HIV infection and AIDS in prisons.

- **WHO and GTZ (2004). Toolkit for targeted HIV/AIDS prevention and care in sex work settings (http://who.arvkit.net/sw/en/index.jsp)**

This is the first ever online tool kit aimed at helping sex workers to protect themselves and their clients from infection with HIV and other sexually transmitted infections. The tool kit is intended for use by people working with female, male and transgender sex workers including programme managers, field workers and peer educators.

- **Bates et al (2004). Vulnerability to malaria, tuberculosis, and HIV AIDS infection and disease. *The Lancet Infectious Diseases* Vol. 4(5-6).**

The first part of the review explores the concept of vulnerability to infectious diseases and examines how age, sex, and genetics can influence the biological response to malaria, tuberculosis and HIV infection. It addresses factors that influence processes such as poverty, livelihoods, gender discrepancies and knowledge acquisition, and provide examples of how approaches to

The homeless

A particular aspect of poverty is being homeless. Having no safe haven, having to earn one’s living from e.g. begging, rubbish collection, petty theft, drug trading or other illegal activities, and being exposed to the influence of thugs, violent customers or abusive police is highly conducive to sexual exploitation and abuse. Women are typically more exposed than men, and children more than adults. Many homeless people, adults and orphaned children and children without family contacts will live many years of their lives as homeless in urban areas. The urban phenomenon of street children, who live either full or part time on the street, is, for example well known. HIV prevalence is often high in such groups.

The incarcerated

While homeless individuals and people with disabilities will be easily seen in many cities in the world, people in prisons will often be overlooked. The standards of prisons usually reflect the socio-economic level of the country, and this in turn means that conditions in many prisons in the world are extremely difficult for the inmates. Overcrowding, malnutrition, infectious diseases, violence, sexual exploitation and physical abuse are usually commonplace.

In countries where intravenous drug use is frequent, this will also continue in jails, and consequently contribute to the spread of HIV. As possibilities to have clean injecting equipment are limited, the risk of HIV spread among intravenous drug users may be higher than among drug users outside prisons.

Pulmonary tuberculosis (TB), a frequent opportunistic infection of people living with HIV, is common in the majority of prisons in low and middle-income countries. As medical care may be inadequate, incomplete TB treatment is also common, and the development of multidrug resistant TB (see Chapter 19 on TB) is often fuelled by prisons. This is currently the case in much of the former Soviet Union.

NGOs have an extremely important role in both helping the implementation of HIV-protective policies in prisons and in the transitional phase when inmates are helped back to society.

altering these processes may have a simultaneous effect on all three diseases. Part 2 addresses the determinants operating at environmental and institutional levels.

- **Open Society Institute (2005). Protecting the Human Rights of Injecting Drug Users: The Impact of HIV and AIDS (www.soros.org/initiatives/ihrd/articles_publications/publications/rights_20050228)**

Compiling statements given at the 2004 session of the UN Commission on Human Rights, this volume argues that unduly strict interpretation of UN drug control treaties undermines HIV prevention efforts by discouraging countries from implementing effective, realistic and compassionate public health policies. The publication's contributors demonstrate that international bodies and national governments must give greater consideration to the human rights – particularly access to HIV treatment – of injection drug users.

- **The World Bank and Center for Interdisciplinary Research on AIDS (CIRA), Yale University. (http://cira.med.yale.edu/globalsurvey/index.html)**

The Global Survey on HIV/AIDS and Disability seeks to understand the impact of the AIDS epidemic on the world's 600 million men, women and children who live with a disability: be it physical, sensory (deaf, blind), intellectual or mental. In addition to the main findings, see the link to "HIV/AIDS and Disability: Capturing Hidden Voices" by Nora E. Groce. There is an extensive list of resources at the website.

The aforementioned groups have much in common. They have little political power, attract limited public interest, are very vulnerable, are exposed to human rights abuses and are extra susceptible to HIV/AIDS.

The clout of international NGOs in combination with the expertise of local and national NGOs can be effectively employed to raise awareness of the plight of these vulnerable groups among politicians, decision-makers, the general public and bilateral and multinational development organisations. Such awareness should also include a focus on how they can be helped effectively and how this also contributes to HIV prevention in the country.

■■■ Entry points for NGOs

■■ In work with individuals from any of these groups, increase their income-generating capacity and improve their food situation – important measures to make them less vulnerable to sexual exploitation;

■■ Use handicap/disability projects and programmes as opportunities to address the whole situation of these groups, including poverty, vulnerability, HIV/AIDS, and sexual and reproductive health issues;

■■ When working with street children, children's villages or AIDS orphans, gradually include life skills aspects that address how to protect oneself from exploitation and sexual and reproductive ill-health;

■■ In work with homeless adults and imprisoned people, make sure to include key aspects of sexual and reproductive health: correct information on safer sex, STI care, family planning including dual protection, counselling and treatment for HIV, AIDS care and TB control. □

10. Emergency situations

In the past decade, major armed conflicts have occurred on all continents, involving the massive material destruction of civilians' sources for survival and forcing waves of populations into migration. Some 50 million of the world's population live in regions currently or recently affected by severe politico-military instability. While the number of conflicts has declined since 1989, internal warfare continues in many countries, the duration of which may extend over decades. At the end of 2003, the world counted 19 major armed conflicts, 17 of which were intra-state, involving protracted situations of population displacement.

In today's conflicts, the toll of fighting is borne by the civilian population: close to 95% of victims who fall in current conflicts belong to the non-combatant population. Another common feature is the displacement of populations seeking to survive either as refugees or as internally displaced, i.e. remaining within the borders of their country. It is estimated that 40 million persons are currently displaced by conflict or disaster. It is also estimated that women and children account for 75–80% of internally displaced populations.

The complex relation between armed conflict and HIV/AIDS

While much has been written on the links between (post-) emergency situations and HIV/AIDS and SRHR, actual evidence is limited and this is partly due to the difficulties in studying these issues systematically during the crisis of an emergency. The population needs related to HIV/AIDS prevention and control, and SRHR needs are as a rule addressed only in the post-emergency phase, once more immediate life-threatening conditions and diseases are under control.

The scarcity of reliable data on reproductive health and HIV/AIDS in emergencies continues to hinder the development of guidelines for effective and relevant responses to emergency-affected populations' needs. Misconceptions about the epidemiology of HIV/AIDS in refugee and internally displaced settings also tend to further stigmatise and exclude rather than assist and protect populations, whose right to health is already in jeopardy by their political and economic marginalisation. One of the misconceptions is that emergency situations, especially wars, inevitably fuel an increase of HIV/AIDS among displaced populations. Recent research has, on the other hand, shown that HIV prevalence is sometimes lower in areas suffering from prolonged conflict than in stable neighbouring locations, which have escaped the experience of war.

MISP

In spite of the complex relationship between armed conflict and HIV/AIDS, a Minimum Initial Service Package (MISP) was developed to respond to the reproductive health needs of populations in the early phase of a refugee situation - which may or may not be an emergency. The MISP is not just kits of equipment and supplies; it is a set of activities that must be implemented in a coordinated manner by appropriately trained staff. It can be implemented without any new needs assessment since documented evidence already justifies its use. The MISP contributes to preventing excess neonatal and maternal morbidity and mortality, reducing HIV transmission, preventing and managing the consequences of sexual violence and includes planning for the provision of comprehensive reproductive health services integrated into the primary health programme in place.

Increased vulnerability to HIV transmission

Certain conflicts have a particular impact on the character of sexual activities in which conflict-affected populations engage. While levels of commercial and coercive sex may increase, a reduction of consensual sexual activity, mainly due to trauma and depression, may be noted.

Increased vulnerability to HIV transmission is likely to occur in conflicts characterised by gender-based violence, including rape and other forms of sexual abuse. During forced migration, material, physical and psychological resources to resist assaults are reduced and fleeing populations may encounter more or less lawless military or paramilitary formations, employing sexual violence as a means of terrorisation. Sexual violence used as a weapon by military groups, to humiliate and degrade displaced populations, may be directed at persons irrespective of their gender and age. Sexual assaults may also take place once refugees and internally displaced are settled in camps, for instance if a minimum degree of security and authority has not been established. When water and firewood must be fetched outside the limits of the camp, women and children are especially at extra risk of sexual aggression.

For most populations, forced migration means poverty. New sources for generating means to survive may not be readily accessible either during escape or when settled in camps. In prolonged conflicts, women, but also orphaned and unaccompanied children and adolescents of both sexes, may be left to fend for themselves. Sex may then be converted into a commodity and sexual favours a means to negotiate survival, security and access to food.

Even as regards consensual sexual activity, conflicts may create situations in which sexual relations imply an increased vulnerability to HIV transmission. Another link between increased vulnerability to HIV and conflict is the erosion of social and/or cultural norms as well as caring and coping mechanisms. A common feature of prolonged conflicts is the gradual breakdown of social structures, such as family and community, that plays an important role in the regulation of sexual activity. The absence of formative caring and guidance may lead to changes in perceptions of identities and contribute to the increase of high-risk situations, especially for adolescents.

Vulnerability to HIV transmission in conflicts may also arise from reduced access to health prevention and care activities, either caused by the breakdown of health infrastructures or the absence of adequate facilities in locations to which displaced populations escape. In current wars, resources which in stable conditions are allocated to the health sector may be diverted to support military activities. Moreover, public health facilities may be deliberately attacked along with other essential components of the infrastructure. One direct impact of destruction is the reduced capacity to screen blood and blood products, the use of infected and non-sterile medical equipment, reduced testing and treatment for HIV/AIDS and the halting of HIV/AIDS national prevention programmes. Displacement may also reduce populations' chances of accessing safe treatment, whether refuge is sought across or inside the borders of the country in conflict.

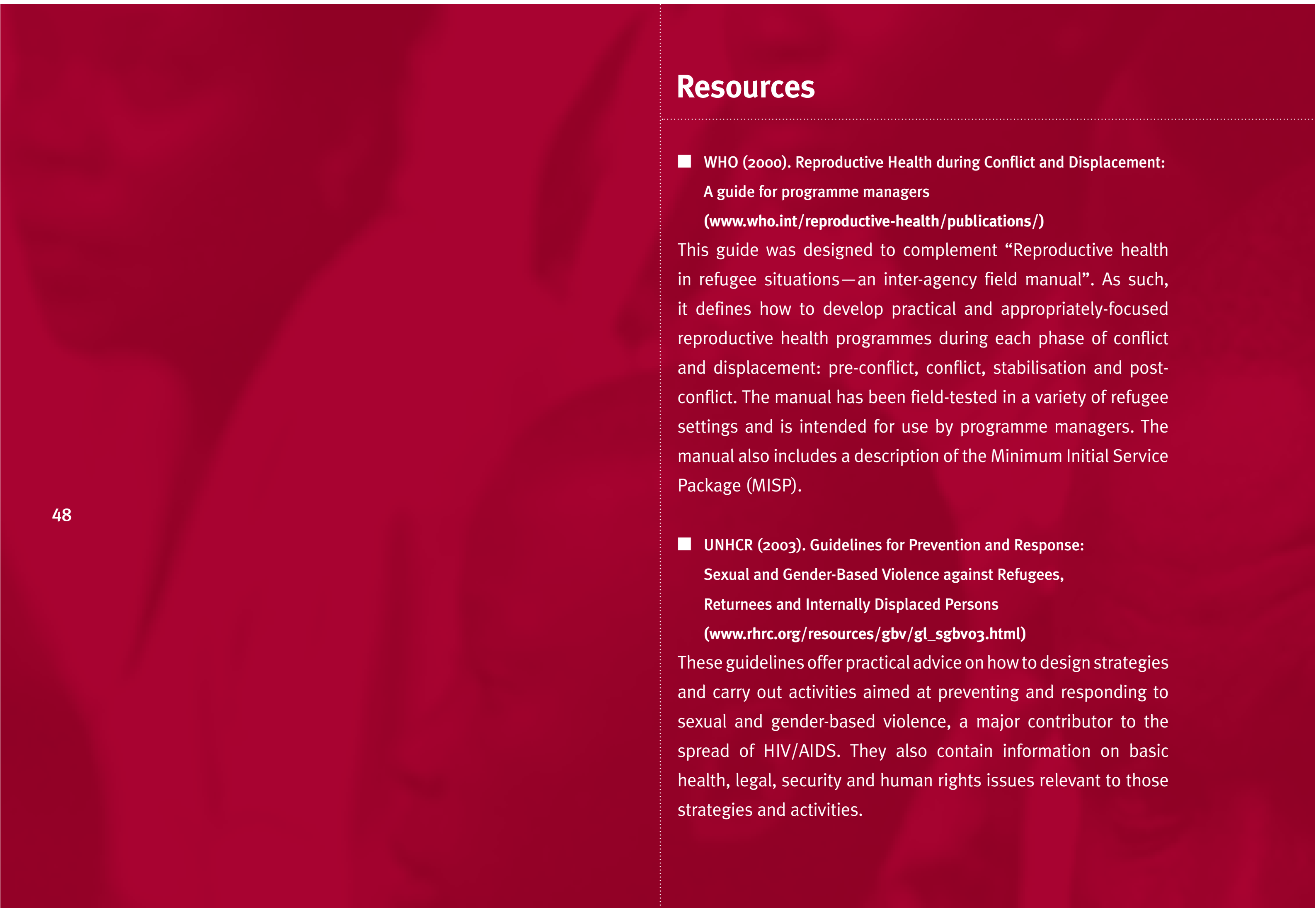
At-risk groups:

Women

Gender-based violence is a common feature of current conflicts and women are at increased risk of being coerced into sex, subjected to rape and other forms of violent abuse. Loss of income generating sources, lack of food and the absence of security may force women and girls into the trade of sexual favours. Gender inequalities may also translate into women and girls' reduced capacity to avoid unwanted sexual relations. The breakdown of family structures caused by forced migration can lead both men and women to engage in situations of high risk, including unprotected sexual activity with an increased number of sexual partners.

Children and adolescents

Children and adolescents, whether orphaned or unaccompanied, are especially at risk during forced migration. In the absence of mechanisms for caring and coping, of family and community structures which offer support and protection, children and adolescents may be abused and exploited for various purposes.



Resources

- **WHO (2000). Reproductive Health during Conflict and Displacement: A guide for programme managers (www.who.int/reproductive-health/publications/)**

This guide was designed to complement "Reproductive health in refugee situations—an inter-agency field manual". As such, it defines how to develop practical and appropriately-focused reproductive health programmes during each phase of conflict and displacement: pre-conflict, conflict, stabilisation and post-conflict. The manual has been field-tested in a variety of refugee settings and is intended for use by programme managers. The manual also includes a description of the Minimum Initial Service Package (MISP).

- **UNHCR (2003). Guidelines for Prevention and Response: Sexual and Gender-Based Violence against Refugees, Returnees and Internally Displaced Persons (www.rhrc.org/resources/gbv/gl_sgbv03.html)**

These guidelines offer practical advice on how to design strategies and carry out activities aimed at preventing and responding to sexual and gender-based violence, a major contributor to the spread of HIV/AIDS. They also contain information on basic health, legal, security and human rights issues relevant to those strategies and activities.

For survival, they may engage in unwanted sexual relations, enrol in military formations, be involved in acts of extreme violence or be introduced to various forms of substance abuse, hereunder intravenous drug use.

Armed personnel

Wars between states are characterised by the proliferation of lawless, undisciplined military formations. This clearly facilitates HIV transmission as unprotected sex is likely to be prevalent. At the same time, UN or other peacekeepers from countries with a privileged financial position may be in the country and may be involved in commercial sexual relations.

Humanitarian workers

Humanitarian workers can face occupational exposure to HIV, sexual violence and risk behaviour which they would not

- **CARE for the Reproductive Health for Refugees Consortium (2002). “Raising Awareness for Reproductive Health in Complex mergencies: A Training Manual” (www.rhrc.org/pdf/Fin1Day.pdf)**

The overall purpose of this training manual is to raise awareness of and build support forreproductive health programming in refugee situations. Specifically, training modules set out to help users initiate, improve or expand reproductive health programming in refugee and forced migration contexts.

- **The Regional Psychosocial Support Initiative for Children Affected by HIV/AIDS (REPSSI) 2004. The journey of life: a community workshop to support children**

This manual is a guide to conducting a workshop designed to raise awareness of the increasing psychological and social needs of children affected by HIV/AIDS, war, and displacement, and work out ways in which the community can find solutions. It is aimed to benefit groups such as community carers, youth and youth leaders, community leaders, members of community-based committees and organisations. It is divided into two sections: a facilitator’s guide to organise the workshop and use the manual, followed by a section that provides the information and activities of the workshop.

- **Inter-Agency Standing Committee (2003). “Guidelines for HIV/AIDS interventions in emergency settings (www.humanitarianinfo.org/iasc/IASC%20products/ FinalGuidelines17Nov2003.pdf)**

These guidelines provide key information for organisations and individuals involved in developing responses to HIV/AIDS during crises. This includes a matrix, designed to present response information in a simplified chart.

necessarily engage in in their home countries. Like armed personnel, they may abuse their position of power. To avoid this situation, they should be given appropriate training before leaving the home country and have proper supervision on these issues while on mission.

Entry points for NGOs

- Emergency relief interventions need to provide special protection for women and children against sexual abuse;

- NGO staff need to be aware of the above risks and be trained on how to deal with them. NGOs can also play an important role in training other NGOs, national forces such as the police and international armed forces playing a peacekeeping role;

- Disaster relief supplies need to include items such as condoms, equipment to manage incomplete abortions and culturally sensitive informational material for staff and displaced populations, in their native language, on how to protect themselves from HIV/AIDS;

- Emergency services should include preparedness for care after rape: social support, emergency contraception and post-exposure prophylaxis for HIV;

- Peacekeepers and humanitarian aid staff should be trained to prevent the spread of HIV/STIs (also by their own action as individuals) and to help control the spread of HIV in post-conflict situations;

- Well placed and respected NGOs can raise a dialogue with stakeholders on the need to be aware of the above risks and initiate coordinated action, such as having a reproductive health coordinator for the emergency setting and ensuring that the Minimum Initial Service Package (MISP) to respond to the reproductive health needs of populations is in place. □

Health-care system factors

The 12 chapters in this section are

While the previous chapters presented societal aspects related to health, the health-care system itself is a key area where NGOs can make an impact on the HIV/AIDS pandemic.

Addressing health-care factors, be they related to family planning, maternal health, youth friendly services or sexually transmitted infections, has the potential to affect a much larger population than activities targeted at changing the behaviour of specific groups of individuals.

Furthermore, this is an area where organisations specialised in HIV/AIDS can draw significantly on lessons learned by those that have worked in the area of sexual and reproductive health services and health policy in general.

11. District level planning for HIV/AIDS

If there is clear vision and commitment, and support from above, district level planning for HIV/AIDS can contribute to major change. This requires that lead district authorities (planning commission or similar) have faced the AIDS challenge and are willing to deal with it. NGOs can play a major role in contributing to placing HIV/AIDS on the district agenda. This entails planning both broad prevention activities in society, and "mitigating" the projected loss of skilled staff and other human resources, for example.

Decentralisation reforms similar to those in, for example, the health and educational sectors have taken place in many sectors. This implies a general move towards devolution of planning responsibility. Such reforms have been ongoing in many countries for some 10-15 years. Decentralisation of decision-making power and budget responsibility from the centre (ministry level) to the district level has become a common trend today. This opens new possibilities for better, integrated planning at the district level, where inter-sectoral collaboration, which is often difficult to achieve at the national/ministry level, actually takes place at the district level. Ideally, the ministries should gradually be taking a more supportive and regulatory role, leaving the decisions and planning to the district authorities.

Box 12. An example of district level planning

To reduce poverty in a certain part of a district, the district authorities decided to, during a 3-year period, endeavour to improve the conditions of the population of this part of the district. Infrastructural efforts were concentrated in the water/sanitation and road sectors to this part, in parallel with extra efforts for the primary schools and the basic health services including VCCT, antiretroviral therapy for certain indications and better guidance on home care for people suffering from AIDS. These different services (in this case water/sanitation, roads, schools and primary health care) are known to act in synergy, and more value for the investments is reached by combining efforts in one area at a time rather than having each sector plan on its own without coordination with the others.

Box 13. Planning needs of select sectors, as regards HIV/AIDS

All sectors need to plan for the loss of trained human resources: train two people where one is needed in high prevalence countries. All also need clear policies on, for example, some of the issues below:

- Finance: on loss of taxation income due to increased poverty;
- Social: to organise support for orphans, home care of AIDS victims and support of poverty-stricken families without bread winner;
- Education: extra educational efforts for girls and orphans;
- Agriculture: projection of change to less labour intensive crops;
- Youth and sports: plan activities for or which include adolescents who are orphans;
- Private sector: establish workplace policies on HIV/AIDS and educational activities.

"Integrated planning" is an expression that has several different meanings and therefore must be defined in every discussion where it is used. It can be clearly defined at four levels:

1. integration of one activity into another in the same programme of a sector (e.g. HIV tests into family planning or life skills education into secondary schools);
2. integrating between levels (health centres and hospitals interact or life skills programme of secondary schools start with first steps in primary schools);
3. a planning process that involves several sectors (e.g. education and agriculture interact), ideally all relevant sectors in a district;
4. district planning involves consultation and planning also

between public authorities, non-profit organisations and for-profit organisations, so that public authorities can direct their efforts to areas that are underserved also when private providers are taken into account.

Ultimately, decentralisation offers new opportunities of planning better locally by holding the potential to strengthen special efforts for disadvantaged populations. The gradual simultaneous improvement of e.g. water, roads, education and primary health care can, ideally, create synergies and be more effective than improving these aspects disjointedly in different parts of the district. NGOs often have strong experiences from limited fields. Their experiences are valuable for district planners and can be drawn upon provided the time is ripe and there is mutual interest.

Simultaneous with sector reform, administrative reform (new district boundaries, perhaps efforts towards more citizen influence/democratisation) and decentralisation, sector-wide approaches (SWAp) and budget support strategies are often introduced. The latter sometimes contribute to the ministerial/central level becoming conceptually “closer” to the “donors”, more distanced from the district level decision-makers. This enhances the need for NGOs to support district level planning.

One of the major failures in many countries when attempting to control HIV has been the disconnect from NGOs and failure to learn from and interact with NGOs. District level planning provides a new opportunity for mutual public/NGO engagement in HIV control at the district level.

Incorporating HIV/AIDS into the regular planning cycle is necessary for all sectors. The planning cycle is a generic process that includes:

- assessment;
- stakeholder consultation;
- options appraisal;
- prioritisation;
- detailed planning and budgeting;
- implementation;
- monitoring and evaluation; and
- new assessment.

This is described in more detail in Chapter 22 on district health planning.

In countries where HIV is common, all sectors need to plan for HIV/AIDS within their respective areas. This entails broad prevention measures in collaboration with others. Planning for

Box 14. Example of planning needs of universities

Like any organisation, universities need to identify and adjust to the impacts of AIDS on their functioning. Firstly, there is staff absence due to own or family health problems, or because of burials. Secondly, they suffer staff loss due to sickness and death. This affects both teaching and the management of university affairs. As a result, thirdly, there is a need for replacement or other measures to maintain the quality of university work. And fourthly, universities are confronted with the economic impact of sick leave, such as support to the family of deceased staff and recruitment costs.

AIDS-relevant issues need to be mainstreamed into the education sector, especially in high-prevalence countries. Staff upgrading and refresher courses should have AIDS as an ever-present item. Planning offices, staff and financial departments need to be enlightened about their duties, while offices responsible for student affairs need to address staff-student relations as they might affect HIV transmission. In practice, few universities in the worst AIDS-affected countries have addressed the impact of AIDS. The normal feature has been to extend some basic services to students, leaving staff to find services “in town”.

Universities must address HIV/AIDS in the form of policies and concrete action plans. This is only possible through the concerted action of engaged people on the campus, national and international NGOs, the media and others that can exert pressure. In addition, ministries of education should be approached to play a stronger role with respect to all institutes of higher learning, including medical schools.

Resources

- **UNAIDS (1997). Guide to the Strategic Planning Process for a National Response to HIV/AIDS (www.unaids.org)**

This four-module guide can be used by countries to undertake strategic HIV/AIDS planning. The UNAIDS draft guidelines aim to introduce the main concepts of strategic planning, remaining flexible enough so that they can be adaptable for planning at a national level in the different regions and can serve as a practical assistant for planners at a district or community level. The core Strategic Planning Guide consists of four modules, each handling one dimension of the strategic planning process: the situation analysis, the response analysis, the strategic plan formulation and resource mobilisation.

- **Family Health International (2004). Strategies for an Expanded and Comprehensive Response to a National HIV/AIDS Epidemic (www.fhi.org/en/HIVAIDS/pub/guide/ecrhndbk/index.htm)**

The eight modules of this book are designed to help all stakeholders address the necessary questions to make informed expanded and comprehensive response decisions. The modules are designed as summary overviews for rapid learning, not as reference documents. Module 4 treats NGO involvement including a section on strategies for NGOs to broaden their impact on HIV/AIDS.

mitigation efforts needs to project the loss of skilled staff and human resources in general, in all sectors, but also the specific needs for each sector (e.g. changes in agricultural practices due to a move to less labour intensive crops and plans for support to orphans in the social sector).

Employing the planning cycle, as summarised above, is useful even in small districts which are still not severely affected by the HIV/AIDS pandemic. By nature, planning processes will initially only cover some of the issues mentioned in the planning chapters, and in this manual in general. Using an agreed upon process and involving stakeholders helps to ensure that the key issues are gradually included into planning, even in small districts, as the pandemic evolves.

■■■ Entry points for NGOs

■■ NGOs should be prepared and willing to engage in district level planning to help control HIV/AIDS;

■■ NGOs' knowledge of what does or does not work in the local setting is extremely valuable and should be regularly shared with district;

■■ NGOs may have stronger contacts with, and are also constituted by, people living with HIV/AIDS and other vulnerable groups. NGOs can help bring forth such voices;

■■ NGOs can help draw from international experiences and international NGOs can interact with national level NGOs to make them stronger and more experienced in district level planning for HIV. □

12. Adolescent services in reproductive health

When adolescents (10–19 years old) and youth (15–24), also called young people (10–24), need reproductive health services they often encounter major difficulties in accessing such services. This is in large part because such health services (for contraception, STIs, maternal health care, abortions or HIV-related services) are typically organised to meet the needs of adults. “Family planning services” often mainly cater for the needs of married women (being “unfriendly” to men and to unmarried, young people) while “STI services” are often organised around the needs of men. Such compartmentalisation and fragmentation is particularly unfortunate because young people are more vulnerable and often more in need of help than adults. They are vulnerable for psychological, social and physical reasons – see Chapter 5 on healthy sexual maturation – and they are more often in need of help because they are often unable to define their problems adequately and to seek appropriate help for them.

Hopefully, most readers of this manual will be able to recollect the first difficult years of awakening sexuality, the many questions and the confusion on where to seek advice. Young people need services where they can get counselling and provision of services. They need a knowledgeable person who does not speak down to them but understands their needs and takes them seriously. A knowledgeable person is empathetic, can provide factually correct information and has good culturally-specific judgement – a person who is good at counselling in its best sense. The range of issues that are problematic for young people is wide and will vary with context. The concerns may be about love, sexuality, coercion, physical development (e.g. asking oneself: “am I normal?”), alcohol or drug abuse, mental ill-health e.g. depression or suicidal thoughts, school problems, unwanted pregnancy or difficult conditions at home (e.g. an abusive, an alcoholic parent or a single mother struggling). While it is clear that being able to respond with “solutions” to all such problems is not possible for any provider, the mere fact that an adult is listening, taking the issues seriously and keeps the discussion confidential goes a long way. Experience also shows that developing youth-friendly services around sexual and reproductive health makes them attractive for young people, including those with problems like the aforementioned. Using sexuality as a justification for seeking such services functions well as an “entry ticket” to ask about other things as well. However, such services may meet resistance in some communities as they can, wrongly, be seen as promoting sexual activity.

Young adolescents (10–14 years of age) are often forgotten, even in programmes that focus on young people’s needs. This age group carries both extra opportunities and extra threats. The opportunities consist of their usually still being part of a family and school context where parents and teachers can support them in their development, choices and information on sexual health issues (including both postponement of sex, and protection) through sound discussion. Just a few years later, the young person may have left school, and the intimate matters may have become taboo at home. The threats, on the other hand, consist of psychosocial and physical vulnerability. It is often unknown to adults how early some adolescents initiate regular sexual activity and the exposure they suffer.

Provision of services means being able to provide the information, commodities and services that young people find difficult both to access and to pay for: contraceptives, tests and treatment for STIs, and voluntary confidential counselling and testing (VCCT) for HIV. Going into a pharmacy and buying condoms is just not an option for many young people in the world, even if they have money, as they are afraid, often with good reason, that shopkeepers will report on their purchase – and assumed sexual activity – to the parents or others. It is particularly difficult for young girls to purchase condoms.

Resources

- **Ipas (2004). Adolescents, unwanted pregnancy and abortion: Policies, counselling and clinical care (www.ipas.org/publications/en/ADOLPOL-E04.pdf)**

This document provides direction on policies, counselling and clinical care that can help prevent unwanted pregnancies and offer abortion-related care that is tailored to adolescents' needs. As such, the issues highlighted are of special importance in making health care "youth-friendly".

- **WHO, UNAIDS, UNFPA, UNODC, Youth Net (2004). Protecting Young People from HIV and AIDS: The Role of Health Services (www.who.int/child-adolescent-health)**

This publication provides an overview of the evidence on health service interventions that are important for information and counselling; reducing risk through condoms and harm reduction; and the diagnosis, treatment and care of STIs and HIV/AIDS. In addition, it describes key strategies for delivering these interventions and outlines the quality characteristics of effective health services for young people.

- **WHO (2002). Adolescent friendly health services: An agenda for change (www.who.int/reproductive-health/publications)**

This document argues that health services need to link with

When proper contraceptive outlets like pharmacies are not an option, young people will often make do with condoms/contraceptives bought at outdoor markets, by unregistered and uneducated salespeople, with the risks for pregnancy and STI/HIV that this implies. For example, condoms kept in a market basket in the heat of the sun for some months are brittle and break easily.

The reasons for young people not relying on health services for their intimate needs are typically fear of judgemental attitudes or discrimination (e.g. "you should not be having sex") or a lack of confidentiality ("I will tell your mother that you were here for pills"), which is further compounded by the fear of meeting family or neighbours in the waiting room, or not being taken seriously.

Organising youth-friendly services that avoid these shortfalls therefore entails some important steps:

- Discussing with local stakeholders how to best provide such services. This would include young people themselves, local decision-makers, schools, HIV services, NGOs and parental groups. This preparatory and planning phase is very important in order for the project not to backfire later. Parents who are being informed about local patterns of HIV infection and/or unwanted pregnancy have a higher probability to accept youth-friendly reproductive health services;
- Selecting staff that are interested in young people and have a knack for talking with them in a horizontal fashion. Such staff persons should be selected for further training, honing these skills further. Staff with judgmental attitudes, who are poorly linked to the realities many young people live in, should not be designated to such services;
- Youth friendly reproductive health services can, in urban areas, be organised as separate services, being open during the periods of the week that young people need them. In smaller towns or villages, such services can be organised as "youth friendly corners" that are open certain hours of the week, where their service rooms, waiting rooms and entrance are reserved for young people;
- The age of access needs to be locally defined. In some countries people over 20 are considered adults, while in others one may decide to give access up to 24 years of age or even more;

the other key services for adolescents, so that they become part of a supportive structure that protects young people against dangers, and helps them to build knowledge and skills. It further calls for and describes the characteristics of an integrated approach to health services for adolescents.

- **UNICEF, UNAIDS and WHO (2002).**
  “Young people and HIV/AIDS: Opportunity in crisis”
  (www.unicef.org/publications)

This landmark report contains important new data about why young people are key to defeating the global HIV/AIDS epidemic, including results from more than 60 new national surveys. It reaffirms that we must accord top priority to making investments in the well-being of young people and to engaging them in the fight against HIV/AIDS, especially in highprevalence countries. The report is the first comprehensive look at the knowledge and behaviour of people aged 15 to 24 relating to HIV/AIDS.

- **WHO (2001). “Sexual relations among young people**
  in developing countries”
  (www.who.int/reproductive-health/adolescent/)

The studies in this review cover a variety of socio-cultural settings. In some, premarital sexual activity is taboo, using

- Co-payment schemes need very careful consideration. While some small contribution can be beneficial, young people often have very difficult financial situations and no means to improve them;
- Reproductive health services for youth function best when there are life skills training/sexual education in schools and for out-of-school youth. In this way, information activities can reach most young people and they can also be advised on where and how to reach services;
- Many stakeholders can be quite pragmatic in referral to or support of youth reproductive health services, even though they may express their views in ways that reinforce their own mandate and prestige as e.g. doctors and clinicians.

■■■ Entry points for NGOs

■■Youth-friendly health services: NGOs should focus on increasing the general youth friendliness of existing health services. Often, adolescents/youth are seen as being in good health, which has the counterproductive effect that they are perceived as needing less attention, which in turn leads to little room for sensitive counselling if special efforts are not made. Increased access to counselling and provision of reproductive health services for boys and girls is needed, and the young people themselves should be involved, to the extent possible, in developing the services. It should be noted that in some countries, the term “youth-friendly health services” is stigmatised, and therefore NGOs should work on improving the “youth-friendliness” of all relevant health services, and not necessarily dub them “youth-friendly health services”.

■■Special counselling for young married women: Offer tailor-made counselling to young married women through existing family planning services. They may become infected by their husbands and they should in addition to family planning services be offered information on HIV transmission

■■Prevention: Use family planning and other reproductive health settings to promote dual protection for protection against unwanted pregnancies as well as STIs and HIV/AIDS, and use HIV/AIDS centres to provide information on contraceptives.

contraception is forbidden among unmarried youth, and abortion is viewed as the only solution to premarital pregnancy among adolescents. In others, premarital pregnancy may be condoned and childbearing among unmarried women is not unknown. A number of recommendations are offered including programmatic recommendations to build negotiation skills, dispel misconceptions, counter sexual violence, involve young people in programme design, tailor fertility regulation services to meet young people's needs, and communicate the message that every unprotected sexual act risks disease and unwanted pregnancy.

■■ **VCCT:** Introduce access to VCCT in existing reproductive health services in order to help young people who are HIV negative to remain so and to counsel those who are HIV positive. Be aware of age limits that might hinder young people under 18 from seeking HIV testing without parental authorisation.

■■ **Violence:** Ensure that special attention is devoted to the risk of partner violence and other abuses that young women might be victims of when they disclose that they have taken an HIV test.

■■ **Post-abortion services:** In addition to counselling on the correct and consistent use of contraceptives, inform the client of the risk of HIV transmission. □

13. Family planning

Anyone who seek advice on family planning should also receive information (and perhaps VCCT) on HIV. As HIV is mainly transmitted sexually, anyone who has sex, and seeks counselling and help for sexually related matters, such as contraception, should also receive information and advice on how to avoid getting HIV or dealing with the suspicion/knowledge of having become infected with HIV. Family planning services can never return to not including HIV or sexually transmitted infections, the way they sometimes were organised before the advent of HIV.

Family planning services (see Box 15) should always provide at least two things: counselling/advice and provision (of contraceptives). It is a rare event that a client does not have questions or want advice. Very often, the advice and counselling are what takes up most of the time. Clients have the right to factual information that as far as possible is unbiased by the views of the provider - real information on the issues that concern the client, such as sexuality, pregnancy, individual health aspects and of course contraceptive options. Seeking help for something as intimate as sexual matters provides an ideal opportunity for the provider to introduce and discuss common societal concerns such as the spread of HIV and how to deal with it under current circumstances. Practically every discussion on family planning with a client needs to include questions on protection against HIV.

Box 15. Family planning

The expression ”family planning” is problematic, as many men and women who seek contraceptive services and help on issues related to contraception, are not ”planning their family”, e.g. because they are not married/cohabitating or perhaps just not interested in ever having a family. “Contraceptive services” is, therefore, a better expression, though “family planning” is still widely employed. In this manual, the two expressions are used interchangeably as many NGOs still have “family planning” in their name, e.g. most of the member associations of the International Planned Parenthood Federation.

Is the client, or the partner(s), practising risky sex? If so, does the client know about how to make sex safer? The provider needs to have a fingertip feel for discussing sex, and also how to provide advice on safer sex in the vernacular of the particular client. “Matching” is a word used by psychologists to connote “choosing a body language and spoken language that corresponds with that of the client”. Getting a horizontal conversation going is the key, not a top-down approach, but a dialogue on the client’s terms, at the same level. As an advisor or a peer educator cannot dictate the client’s sexual practices, they must provide expert information in a manner that makes the information interesting, credible and hopefully useful.

However, many providers were trained during a different era, when target-driven approaches and demographic goals were at the forefront, times when clients should not ask too may questions and should not be given too many options. Today, we know that the International Conference on Population and Development programme of action from 1994 is a confirmation that people want contraceptives and should not be coerced to use them, that their free choice enhances the use of contraceptives, including condoms, and that quality information including accurate information on positive and negative aspects of available contraceptives increases credibility. Neglecting to inform about common side-effects turns clients away – they are likely to not come back once they have found out that providers “misled them”.

Contraceptives

All contraceptives have strengths and weaknesses. There is no contraceptive that is ideal for everyone. Being honest about the

Resources

- **Pruyn N and Cuca Y (2002). Analysis of Family Planning / HIV/AIDS Integration Activities within the USAID Population, Health and Nutrition Center (www.dec.org/pdf_docs/PNACR591.pdf)**

The United States Agency for International Development (USAID) is one of many development agencies seeking to stop the spread of HIV/AIDS using strategies ranging from providing information and education, to providing prevention and care services. This report presents the results of a survey conducted by Advance Africa and the CATALYST Consortium in order to gain an overall understanding of the number and scope of family planning/HIV/AIDS integration activities, including dual protection, conducted by USAID's Population, Health and Nutrition Center cooperating agencies.

- **Strachan M et al (2004). Is there a role for family planning in the context of HIV/AIDS programmes? (www.dec.org/pdf_docs/PNACX558.pdf)**

This working paper from the POLICY Project analyses how international guidelines and national policies on HIV/AIDS, voluntary, confidential counselling and testing (VCCT) and prevention of mother-to-child-transmission (PMTCT) address family planning. Looking at 16 countries with high HIV prevalence, the study finds that more than three-quarters of the policies

features of each contraceptive that is available implies also being sensitive to the needs of the client, including questions, fears and suspicions, contraceptive safety and the issues related to control of the contraceptive. "Safety" can mean different things: some will perceive it as freedom from side-effects, while others will interpret it mainly as how effective the contraceptive is against pregnancy. It is not uncommon that women cannot discuss contraception with their partner. Many couples might, in reality, have different desires for how many children they want and a woman may want to conceive (or not to conceive or to choose a particular method) against the wish of her husband. This has implications for contraceptive choice. There are also particular aspects for each contraceptive, such as effects on bleeding patterns, cost, availability and effectiveness when forgotten or skipped. The more contraceptives we have – and today we have some 15 methods available (see Box 16) – the more demanding is the task of the provider.

Five special aspects are extra important in family planning today:

Box 16. Contraceptive methods

Today's contraceptives, roughly in order of contraceptive effectiveness, which will depend on consistency in correct use of method:

- Male sterilisation
- Female sterilisation
- Long-term injectables (monthly, or every three months)
- Implants (release progestagens)
- Vaginal rings (release progestagens, or estrogen-progestagen)
- Hormone releasing intrauterine devices (IUD)
- Combined contraceptive pills
- Copper releasing IUD
- Mini-pills (progestagen only)
- Diaphragm with spermicide
- Male condom
- Female condom
- Spermicide (foam, cream, sponge)
- Lactational amenorrhea method (LAM)
- Coitus interruptus
- Rhythm methods (periodic abstinence)

reviewed mention family planning. However, the primary focus tends to be on referral to family planning services, provision of information on contraceptives or the equipping of family planning clinics with HIV/AIDS facilities. The paper concludes by outlining strategies for achieving effective integration of family planning into VCCT and PMTCT.

- **Johns Hopkins University (2001). The essentials of Contraceptive Technology: A Handbook for Clinic Staff**

This very user-friendly book, produced with WHO and USAID, reviews all forms of contraception with definitions, questions and answers and medical eligibility. NGOs should make sure that this is on the shelf of all clinics in the countries where they work. Low-cost bulk purchases of the book can be made from: www.jhuccp.org/pubs/ect/.

- **WHO (1999). Integrating STI Management into Family Planning Services: What are the Benefits? (www.who.int/reproductive-health/publications)**

The integration of STI and family planning services is regarded as an important criterion for improving the health of women. Comprehensive reproductive health needs are often not met in family planning clinics, the usual and sometimes only source of reproductive health care available to women, and STI/HIV

1. Information on dual protection, i.e. having good protection against pregnancy and good protection against STI/HIV. This in turn means discussing condom use.

2. To be able to provide advice on emergency contraception. Opening up the possibility for clients to seek help after unwanted unprotected sex – with the risk of unwanted pregnancy and STI/HIV – gives an entry point to discussing and/or providing emergency contraception and discussing unsafe sex and what to do about it.

3. Opening doors to voluntary counselling and testing for HIV through VCCT. Every family planning provider in the world today needs to be able to give “pre-VCCT counselling”, meaning knowing the basic facts about VCCT and where to obtain specialist VCCT.

4. Contraceptive providers must be able to deal with the most common STIs. This may imply routine screening for such infections (e.g. a syphilis test) or syndromic treatment (treatment by symptom according to pre-agreed protocols/guidelines, but without laboratory support). Please see Chapter 16 on care for sexually transmitted infections for more details. On STIs, one can, paradoxically, conclude that a client that has acquired an STI and met a good provider today is a fortunate person: being explained the risks of unprotected sex (leading to the STI) and learning the basics of safer sexual practices may help this person to not acquire HIV tomorrow.

5. Decrease to the extent possible the administrative and medical barriers to acquiring contraceptive methods. Apply WHO technical guidance.

■■■ Entry points for NGOs

■■Ensure that contraceptive services (“family planning services”) in the area fulfil the basic quality requirements: that they are available (as regards distance, client cost and capacity) and culturally acceptable, including a reasonable variety of methods;

■■Ensure that in addition to married women, others can access the services, such as men, unmarried women and young people;

Resources

concerns are often not addressed at all. This review documents current experience with the integration of STI management into family planning services, in order to clarify the public health benefit of this integration, and highlight the operational changes.

- **Supply Initiative.**
  (www.rhsupplies.org)

Each year, greater numbers of people in the developing world are seeking out condoms and contraceptives for family planning and protection against STIs/HIV. "The Supply Initiative" was set up to call attention to this crisis as well as to increase the availability and efficient use of human, institutional and financial resources for reproductive health supplies. On their website, you will find more details on reproductive health supply shortages and the activities of the Supply Initiative, a joint effort of four NGOs.

- **Callahan K, Cucuzza L (2003). Family Planning Plus:**
  HIV/AIDS Basics for NGOs and Family Planning Program Managers
  Integrating Reproductive Health and HIV/AIDS for NGOs, FBOs
  & CBOs. Centre for Development and Population Activities (CEDPA)
  (www.phishare.org/documents/cedpa/705/)

This curriculum was developed to provide staff of NGOs and the community at large a deeper understanding of the dynamics and effects of HIV/AIDS and to sensitise them to the current issues and challenges that people living with HIV/AIDS face.

- Ensure that PLWHA can also access services and that their reproductive health needs are met;

- Ensure that contraceptive services also provide information and access to dual protection, emergency contraception and initial information on voluntary counselling and testing for HIV;

- Ensure that basic STI services also are integrated into contraceptive services, and that cross-referral to STI services function;

- Ensure the quality of care, in accordance with WHO guidance. □

14. Maternal care

Maternal health care includes antenatal care, delivery care, newborn care and postpartum care. In all of these, HIV prevention and control is involved, both from the perspective of the pregnant/birthing woman, her baby and the staff involved. Pregnant women and new mothers may be HIV infected and have developed AIDS, and as a result need special attention; there is a risk of vertical transmission (from the mother to her baby); and in the delivery room extra staff protection is needed as there is infected blood and amniotic fluid.

Currently, preventing mother-to-child transmission of HIV (PMTCT) is receiving much attention. This is because we now know of very effective methods to prevent such mother-to-child-infection with HIV, methods that were unknown to us ten years ago. It is important to state that this is only one of several reasons to focus on pregnant women in respect to HIV/AIDS. WHO defines three different sets of action as important during pregnancy:

1. Help prevent more women from becoming infected with HIV. This is called primary prevention. Interventions to this end include information, education – of women, men and families – and voluntary confidential counselling and testing (VCCT).

2. Attend to the needs of pregnant women infected or suspected of being infected with HIV. This includes VCCT, information on abortion within the limits of the law, treatment of opportunistic infections including tuberculosis and family planning.

3. Help prevent mother-to-child transmission of HIV.

In antenatal care (ANC), major HIV-related issues are the three aforementioned. Most women in all countries come to ANC at least halfway into pregnancy. This provides unique opportunities to discuss both maternal and newborn health issues, screen for opportunistic infections and offer VCCT. Unfortunately, ANC is still in many places hampered by rather ineffective interventions inherited from "the West". Examples of this are routine weighing and multiple routine visits. Adapting the interventions of ANC to the reality of the respective country is thus essential. Here are some key components, many of which can be carried out as group activities with a number of pregnant women jointly (marked G):

- informing about HIV and providing advice on where to get VCCT (G);
- informing about possibilities to prevent HIV transmission to newborns (G);
- informing about malaria (that can affect women with HIV more heavily), the use of insecticide-impregnated bednets and the use of intermittent (2-3 times) antimalarials in pregnancy (G);
- information about breastfeeding in general and the link to HIV transmission (G);
- information about family planning options (G);
- checking nutritional status by simple inspection;
- asking for a cough in thin women to check for tuberculosis;

vdiscussing previous pregnancies, births and children;

- providing syphilis tests routinely, with one stop treatment;
- offering syndromic treatment for suspected sexually transmitted infections and providing for follow-up of male partner(s);
- providing follow-up support to women known to be HIV positive, offering antiretroviral drugs to prevent mother-to-child transmission and giving detailed baby feeding advice;
- referring women with the suspicion of pulmonary tuberculosis to a tuberculosis programme;
- providing treatment for common opportunistic infections; and
- offering long-term antiretroviral treatment to HIV-infected women, when available, and indicated.

In delivery care, the main additional issues are to:

- provide antiretroviral therapy during delivery if this has been discussed and agreed on (the mother is given the drug nevirapine

Resources

- **Abou-Zahr CL, Wardlaw TM (2003). Antenatal services provide entry point to range of health programmes in developing countries (www.who.int/reproductive-health/docs/antenatal_care.pdf)**

This report, produced by WHO, analyses patterns and trends in antenatal care use in developing countries from 1990 to 2001. The main findings include that the use of antenatal care in developing countries rose by one-fifth during the 1990s, and the smallest increases were in sub-Saharan Africa. Key determinants of antenatal care use were household wealth, place of residence and level of education. The report concludes that antenatal services present many unexploited opportunities, not only for improving the health of women and their infants, but also for providing entry points to a range of other programmes, including malaria, TB, nutrition, HIV/AIDS (particularly prevention of mother to child transmission) and other STIs.

- **Santarelli C, WHO (2003). "Working with Individuals, Families and Communities to Improve Maternal and Newborn Health" (www.who.int/reproductive-health/publications/RHR_03_11/)**

The Making Pregnancy Safer initiative was launched in 2000 to enhance WHO's efforts in Safe Motherhood. The initiative states that both the improvement of health services and actions at the community level are required to ensure that women and their newborns have access to the skilled care they need,

during delivery to reduce the risk of transmitting HIV);

- giving further support to the mother;
- mode of delivery (a Caesarean section may be desirable under certain circumstances);
- protection of staff in delivery room (e.g. plastic apron, plastic glasses and gloves) and safe disposal of placenta (placenta pit);
- proper disinfection of all blood and amniotic fluid;
- ensuring that breastfeeding is initiated well;
- advising on a follow-up visit including family planning.

For the newborn, the main question that arises is the feeding option. The feeding option for most babies of mothers known to be HIV infected is full breastfeeding for six months and thereafter weaning foods. Artificial feeding will be an option for only few HIV-infected mothers due to logistics (cost and availability of formula and safe water) and discrimination issues (in many settings initial and total artificial feeding will be interpreted by the surrounding as the mother being HIV infected, leading to severe discrimination).

The postpartum period, during the first weeks after birth, when mothers/newborns are at home again, has until recently been largely neglected by maternal health care and relatively few programmes address this period sufficiently. This is actually a time period that has more complications for mothers and newborns than commonly recognised. Overall, WHO today recommends all health systems to either provide a health-care contact for all mothers and newborns during the early (1-2 weeks after birth) postpartum period or, at a minimum, have health systems geared to the urgent needs of mothers and babies during this vulnerable period. This means that maternal-child health-care staff should be able to diagnose and treat common complications in mothers and newborns, be aware of how to support the establishment of full breastfeeding and also be trained to identify common HIV-related complications and know how to manage these.

During pregnancy, birth and the postpartum period, many women in the heavily HIV-stricken countries will present HIV-related infections or AIDS, and this is changing the panorama of maternal ill-health. Maternal deaths due to HIV/AIDS are increasing throughout sub-Saharan Africa, for example, and staff when they need it. This document proposes a framework for the development of interventions at the individual, family and community levels to improve maternal and newborn health.

- **UNFPA/EngenderHealth (2004). HIV prevention in maternal health services: a training guide (www.engenderhealth.org)**

This training manual, produced by EngenderHealth, provides guidance on how to integrate prevention of HIV and other STIs into maternal health services. Its objective is to build the capacity of programme managers and staff to meet the HIV and STI needs of women who are pregnant or who have given birth. It includes a detailed training curriculum, with step-by-step guidance on each session.

- **UNAIDS and WHO (1999). HIV in Pregnancy: A Review (www.who.int/reproductivehealth/publications/rhr_99_15/)**

This paper consists of a summary of what is known about HIV in pregnancy, transmission of HIV from mother to child and interventions to prevent transmission. Section two provides some suggestions on the appropriate management of HIV-positive women during pregnancy, delivery and postpartum. The third section lists guidelines for infection control and safe working conditions with regard to HIV in pregnancy.

must be prepared to deal with these complications. The mother-baby “dyad” clearly also depends on the health of the mother, and staff must know how to institute supportive measures for the baby when the mother is ill.

Entry points for NGOs

- NGOs have an important role in awareness raising during pregnancy, both as regards VCCT and the prevention of mother-to-child transmission of HIV;

- NGOs can train skilled attendants in how to protect themselves against HIV/AIDS and how to counsel HIV-positive pregnant women or new mothers;

- NGOs can work to set up prevention of mother-to-child transmission of HIV programmes at clinics and hospitals by inter alia working to improve drug procurement, training providers and counselling pregnant women and their families;

- NGOs have a role to play in the many fields involved in promoting breastfeeding and at the same time preventing vertical HIV transmission: public awareness raising and preparing for breastfeeding, helping mothers breastfeed exclusively for six months and then wean, and monitoring that the International Code for Marketing of Breast Milk Substitutes is followed and substitutes are not overly marketed;

- NGOs should also help provide increased vigilance of poor women’s health during pregnancy, birth and postpartum. □

15. Abortion and post-abortion care

Abortion means pregnancy interruption. Most people mean "induced abortion" when they speak about abortion, but some will also include "spontaneous abortion", i.e. miscarriage. Spontaneous abortion ends about 15% of all pregnancies and is fairly constant around the world. Even though some women who suffer from miscarriage need basic health care, the main public health challenge surrounding abortion is related to unsafely induced abortion. Both unwanted pregnancy and a sexually transmitted infection, including HIV, are not only consequences of sexual intercourse, but consequences of unprotected intercourse, and sometimes intercourse that the woman either did not want or could not control. Induced abortion and HIV infection are different results of the same unsafe behaviour. Working with HIV prevention, it is difficult to ignore the challenge of abortion, as many women who seek (post)abortion care need guidance and protection against future HIV infection – and another unwanted pregnancy. Some women will also seek abortion because they are HIV infected.

Induced abortion is a public health challenge in all countries of the world. Everywhere, even in countries with the best of sexual education and contraceptive services, some women will end up with unwanted pregnancies that they wish to discontinue. This can be because contraception failed, because they had not imagined they could get pregnant or because their life situation changed (e.g. their relationship ended). In a number of countries, pregnancy interruption is available on demand in early pregnancy. Another group of countries only allow induced abortion under certain circumstances, most commonly a serious health threat to the woman's life, important foetal impairment or pregnancy after rape or incest. A third group of countries do not allow induced abortion under any circumstances, even if it means the pregnant woman may die.

However, there are many abortions in all countries of the world. Where they are difficult to access legally, they will be accessed illegally: either safe, illegal abortions provided at high costs by medical personnel, or unsafe "back-street" abortions provided by unskilled providers. As "back-street abortionists" rarely have the skills to perform an abortion safely, women who cannot afford anything else often end up either with severe, often life-threatening complications in hospital, or dying from the intervention. Self-induced unsafe abortion, by the intake of chemicals or drugs has long been common in some countries with restrictive abortion laws. This is very dangerous and kills thousands of women every year.

In recent years, a much safer option has become available: the intake of an antiprogestagen substance in early pregnancy will cause safe abortions in the majority of women, while a small minority need a health-care visit to empty the womb afterwards. This substance, misoprostol, originally marketed as a medicine against gastric ulcer, Cytotec, is today sold on the black market in many countries and women are using it as a drug that interrupts pregnancy. Where, for example in Latin American countries, abortion is restricted, most hospital gynaecologic departments 15 years ago were almost filled with women being treated for complications of induced abortions. Today, one sees few of these women. This is partly because abortions can be performed at home, with antiprogestagens.

Legal or not, such treatment has become a lifesaver for many women with unwanted pregnancy. Irrespective of how others see the woman's wish for an abortion, in religious or moralistic terms, many women end up in extremely difficult situations. The poor, single woman with many children to provide for, the very young girl, who often has been coerced into sex and now cannot take care of a child, or the woman who has been raped all have exceedingly difficult choices: borrow much money to go to a nurse or doctor and get a safe illegal abortion, suffer the risks and exploitation of going to an unskilled provider or try something potentially dangerous on her own at home.

Women who have had an induced abortion with an unskilled provider will often end up bleeding. The bleeding continues because the womb is not empty. This will threaten the woman's life – she needs a skilled provider to provide post-abortion care (see Box 17). In trained hands, this is a simple procedure that can be carried out at a health centre. Moreover, women suffering spontaneous abortion may end up bleeding. Providing adequate post-abortion care is thus one important intervention that should be provided everywhere, as no country has restrictions on post-abortion care. After all, the abortion has happened and the woman has a potentially life-threatening complication.

Abortion and HIV

A special situation is when a woman wishes to have an abortion because she has an HIV infection, and perhaps even symptoms of immune deficiency. Unfortunately, countries with restrictive laws may either not see this as justification for legal abortion, or simply not provide access to abortion services even though the woman has legal rights to it. A number of countries that give some legal room for abortion, under certain circumstances, do in actuality not provide the services for the intervention. This may be for logistical or economic reasons, but is in reality more often for hypocritical and "bureaucratic" reasons – there is an unwillingness to deal with this whole area. Gender discrimination is one strong factor behind this in many instances. However, in some countries the contrary occurs: HIV+ women or AIDS patients are coerced into abortion.

Finally, there is a clear relation between abortion requests by HIV-positive women and the availability of antiretroviral treatment and/or prevention of mother-to-child transmission. By providing antiretroviral treatment to prevent transmission of HIV to the newborn, the demand for induced abortion due to HIV/AIDS is reduced.

Box 17. Abortion-related mortality

A 17-year-old female high school student came to the emergency room in a sub-Saharan country. The nurse reported that she had fainted while waiting for the doctor. The girl herself told the doctor that she had been two months pregnant, and had had a miscarriage. Her blood pressure was normal, she was only bleeding slightly from the womb, and it seemed that the complete miscarriage had already happened. She was put into the ward for observation and given antibiotics. Twelve hours later, she became severely ill, with high fever and unconsciousness. The family now told the doctor that she had actually visited an abortionist because the pregnancy was unwanted. The doctor re-assessed the patient, took her to the operating room and did the best possible. In spite of this, it was now too late, and the girl died on the operation table. This is a very common story. About 68,000 women die each year from unsafe abortions.

■■■ Entry points for NGOs

■■ Raise and discuss the issue of post-abortion care in the country. When relevant, support the training of skilled providers (midwives, nurses, doctors) in post-abortion care in the following ways:

- ■ ensuring adequate primary treatment (emptying the womb in a safe way, giving antibiotics when needed);
- ■ giving contraceptive counselling and provision;
- ■ providing HIV counselling and VCCT as required; and
- ■ non-discriminatory treatment;

■■ Support the provision of abortion services to the fullest extent of the law. HIV counselling and contraceptive counselling should be available at the same time, and at the same service point;

Resources

- **WHO (2003). "Safe Abortion: Technical and Policy Guidance for Health Systems".**

Unsafe abortion is one of the main causes of maternal mortality and morbidity even though it is legal in a variety of circumstances in almost all countries. This document provides the definitive guidance on the subject, including on contraception after abortion, a key entry point for HIV/AIDS programmes. It also calls for an enabling policy environment to ensure ready access to high-quality services including the particular needs of HIV-infected women.

- **IPAS. Global Abortion News Update. (www.ipas.org)**

The NGO IPAS runs a global abortion news updates feature on its website. It provides an overview of new developments in abortion law and policy around the world, including links and contact details. This site also has valuable resource such as "Making safe abortion accessible: A practical guide for advocates" and "Abortion methods and Post-abortion care".

- **The Global Gag Rule Project. (www.globalgagrule.org)**

The global gag rule was imposed by President Bush in January 2001, purportedly to reduce abortion by reducing access to abortion services around the world. Instead, the policy is having a damaging impact on international family planning as documented at the above website. This hampers the ability to provide basic reproductive health-care services and weakens organisations working in the frontline against HIV/AIDS, as described in a fact sheet on the subject.

■■ In countries where unsafe abortion is a significant problem that is poorly acknowledged, advocacy oriented research can highlight injustices in this area, and international NGOs have a special role to play here. Where gender inequity and female disempowerment is a major background cause of the abortion rate, HIV infection is also a major risk. Raising this double vulnerability of groups of women, especially young girls, is an extra lever in advocacy work;

■■ All countries can reduce the number of unsafe abortions with certain key interventions, the choice of which will depend on the law. Increased efforts in education and contraceptive counselling and provision can be carried out everywhere. Emergency contraception, also known as the "morning-after pill", (see Chapter 13) should also be strongly promoted;

■■ Ensure that HIV counselling and VCCT are integrated parts of both abortion care and post-abortion care;

■■ It is particularly important when dealing with abortion, that arguments, messages and activities are carefully developed, especially when linked to HIV, due to the opposition to legal abortion that exists, to some extent, in all countries. Adapting to the local context, but still addressing the major needs of particularly poor and young women, is a key area where sexual and reproductive health and HIV/AIDS services overlap. □

16. Care for sexually transmitted infections

STIs are infections mainly transmitted by sexual intercourse. STIs replaced the term sexually transmitted diseases (STDs) in 1998 in order to address the inaccuracy of calling human immunodeficiency virus (HIV) a disease (AIDS is the disease caused by HIV) and to better incorporate asymptomatic infections such as Chlamydia, which causes pelvic inflammatory disease, for example.

STIs increase the risk of acquiring or transmitting HIV. The reason for this is that many STIs cause sores (ulcerative STIs), which are openings on the skin in and around the genitals. These sores, as well as the inflammation caused by STIs, make it easier for HIV to get into the body. Consequently, detecting and treating STIs early is important to prevent HIV transmission.

People can have STIs without having symptoms (non-ulcerative STIs), such as is often the case with Chlamydia in women. They can be asymptomatic and may not realise that they are infected. But even if they have no symptoms, the infection can still be transmitted to others when having unprotected sex.

There are two broad categories of STIs: those that can be cured and those that are incurable. Curable STIs can be treated with medications, usually antibiotics. These STIs include syphilis, gonorrhoea and Chlamydia. Incurable STIs include HIV, hepatitis C and herpes, which are caused by viruses. Although they cannot be cured, some treatments are available to prevent, relieve or reduce the symptoms as well as to lower the risk of HIV transmission.

Clearly, prevention and treatment of STIs is an important strategy both for the prevention of HIV and for the improvement of reproductive health conditions. Apart from the fact that STIs can contribute to HIV infection, untreated STIs can lead to gynaecologic or neonatal complications for women and infants, such as abortion, infertility, pelvic inflammatory disease, cancer or blindness in newborn babies. HIV can, in turn, worsen the symptoms and presentation of many STIs, and thereby contribute to the spread of those, and of HIV.

Box 18. How STIs are treated

Most STIs can be cured with the use of medicine. The provider must take a proper history, make a diagnosis and prescribe the right treatment. Buying medicine by oneself and taking the wrong medicine can be dangerous. A certain kind of medicine will only cure a certain kind of STI and only a specially trained health-care provider can determine this. Unfortunately, STI patients sometimes stop taking their medicine after 3 or 4 days because they feel better. However, because they do not complete the treatment as prescribed, the STIs are not totally cured and resistance can develop.

In recent years, STIs have increasingly been effectively treated by "syndromic treatment", meaning with the help of so-called algorithms. Algorithms are formally agreed upon "decision-making trees" that take the history, current symptoms and often physical examination results into account in the country context. Careful use of these decision-making tools by specially trained staff (low level staff can also use these when well trained and supervised) contributes greatly to increased population access to STI treatment, even in the absence of laboratory tests. "Syndromic treatment" thus means evidence-based treatment based on a defined set of symptoms, or "syndrome".

In parallel, better, easy to use diagnostic lab test are being developed. However, some that already exist, e.g. the rapid test for syphilis, are not being used as much as they should.

For bacterial infections, antibiotics are used. For viral infections, there are anti-viral drugs or symptomatic treatment, e.g. bathing the blisters in special warm salty water, taking painkillers and applying preventive measures to stop spreading the infection.

When a person is treated for an STI, their partner(s) should also be treated at the same time, or at least before they have sexual relations again – otherwise the treated person may get re-infected by the untreated partner.

As prevention strategies of STIs including HIV are mainly

Resources

- **UNAIDS and WHO (2000). Consultation on STD interventions for preventing HIV: what is the evidence (www.who.int/hiv/pub/sti/pubevidence/en/)**

This report presents the scientific evidence pointing to the importance of STD control and the impact this can have on HIV transmission. It also discusses some of the main programmatic and policy issues related to STI control.

- **IPPF (2002). "Programme guidance on counselling for STI/HIV prevention in sexual and reproductive health settings".**

This publication targets counsellors, health workers, educators and others working in STI/HIV/AIDS. It aims to improve information on STI/HIV prevention, safer sex, pre- and post-HIV antibody testing and related issues for those who work with young people, male and female clients, individuals and couples.

- **Dallabetta G, Laga M, Lamptey P (eds) 2004. "Control of Sexually Transmitted Diseases: A Handbook for the Design and Management of Programs" (www.fhi.org/en/HIVAIDS/pub/guide/stdhandbook/index.htm)**

This handbook addresses the full spectrum of issues that STI managers at the national and local levels must consider when designing and implementing STI programmes. It is not a clinical text but instead provides an overview of the topics most salient

Box 19. Combining STI and HIV prevention in practice

The NGO Pathfinder International in India is working with reproductive health and HIV/AIDS issues. Currently, Pathfinder International is implementing a five-year project in India called "Targeted Interventions for Groups at Risk" (TIGRIS). The overarching goal of this project is to decrease the spread of HIV among vulnerable groups such as female sex workers and intravenous drug users. The project, which is in the state of Maharashtra, tries to do this by increasing awareness and treatment-seeking behaviour, including regular STI screening, with a combination of clinic and community-based STI diagnosis and treatment, HIV education and prevention and behaviour change programmes.

Pathfinder also has another project in the state of Bihar in India, which combines behaviour change communication initiatives with improved access to family planning and reproductive health services, including STI and HIV/AIDS prevention.

Both projects are good examples of how services and behaviour change interventions for STI and HIV/AIDS prevention can be integrated. For more about Pathfinder International's work in India, visit: www.pathfind.org.

abstinence, non-penetrative sex or condom use, many behaviour change interventions for STI and HIV prevention can be integrated. As part of their counselling of clients, maternal and child health/family planning clinics should also discuss contraceptive use including the use of condoms. It is therefore a good opportunity to inform clients about the importance of condom use in relation to STI and HIV prevention. For more on dual protection and the female condom see Chapter 13 on family planning.

However, negotiating condom use is not easy because of the sensitive nature of sexuality. Women, in particular, may find it difficult, if not impossible, to negotiate safer sex with their partners due to gender inequalities and a lack of power within sexual relationships. Partners may equate a request for safer sex with an indication of unfaithfulness and may react negatively, even violently, or may react by withdrawing financial support or terminating the relationship. Furthermore, men play a dominant role in deciding whether their partners can initiate the use of contraceptives and whether it is acceptable for the children to seek information about sexual and reproductive health.

Involving men in family planning counselling is, therefore, to their programmes, such as training, surveillance, curative and preventive services and evaluation.

- **Lamptey PR, Gayle HD (eds.) 2002. HIV/AIDS Prevention and Care in Resource-Constrained Settings. A Handbook for the Design and Management of Programs. Arlington, FHI publications (www.fhi.org/en/HIVAIDS/pub/guide/HIVAIDSPreventionCare)**

Chapters 14-16 of this comprehensive volume look at case management in primary health-care settings, issues in STD control for special groups and programme management and evaluation. The handbook is intended to be used by programme mangers, technical and programmatic field staff, the staffs of donor and international partner agencies, health-care providers and field researchers.

- **WHO (2003). "Guidelines for the Management of Sexually Transmitted Infections". (www.who.int/reproductive-health/publications/rhr_01_10/01_10.pdf)**

This document covers not only how to treat all STIs, but also aspects of case management, selection of drugs, considerations underlying treatments and a special section on children and adolescents.

of paramount importance. However, it is often more difficult to counsel about correct and consistent condom use, as this is perceived as a very sensitive issue, which to a larger extent requires privacy and confidentiality during counselling.

Ultimately, people who seek care for STIs are at high risk of HIV. Good and empathetic counselling (and treatment) of today's syphilis or gonorrhoea patients can help them not get HIV tomorrow.

■■■ Entry points for NGOs

■■Support the development, and use of services that screen for and manage STIs – both as stand-alone STI services and as STI screening/treatment in e.g. antenatal care (especially for syphilis), family planning and youth reproductive health services;

■■STI screening of PLWHA: This is important because the infection influences other infections and diseases, including untreated STIs. Also, both HIV and STIs spread easier when there is co-infection of HIV and STI. Organisations working with female sex workers or injecting drug users could set up STI clinics, and PLWHA networks should have information about existing STI clinics available for the general population. NGOs can further contribute to this by helping to map such services;

■■Youth friendly services: As adolescents and other young people are particularly vulnerable towards becoming infected with an STI or HIV, designing and implementing services that specifically cater to their needs is extremely important. To increase the success rate of youth friendly health services, young people should ideally contribute to their design and, to the extent possible, help run them. □

17. Voluntary confidential counselling and testing

The vast majority of PLWHA in low-income countries are unaware that they are infected, a factor that substantially weakens efforts to respond effectively to the HIV/AIDS epidemic. Due to widespread stigma and discrimination towards PLWHA, low life-expectancy levels and a lack of treatment options, many individuals do not see an incentive to be HIV tested.

VCCT stands for voluntary, confidential counselling and testing and is mainly made up of two components; counselling and testing. However, a C has been added to the concept to emphasise the importance of confidentiality, hence VCCT. Many people are afraid to seek HIV/AIDS related services because they fear stigma and discrimination from their families and community as well as loss of employment. Confidentiality is therefore an essential component of VCCT. At the same time, disclosure of HIV serostatus to partners and families is important. VCCT services should always be anonymous and results should never be given over the telephone or disclosed to another person. Ideally, clients are identified only by numbers even if they are registered under their names.

VCCT is regarded as a very central intervention both in the response to the HIV/AIDS epidemic and in the fight for the fulfilment of SRHR, as it bridges interventions within SRHR and HIV prevention and AIDS care and support. During VCCT, if the test result is negative, the client should be informed of how to remain HIV negative. If the client is found to be HIV positive it is important that the person knows how to prevent transmission of the virus to others sexually, through child birth or by breastfeeding. Additionally, referral to clinical settings for care and treatment and possibly also to PLWHA-networks, where the person might be able to find peer support, is important.

Figure 1 provides a good overview of VCCT and in what intervention areas VCCT can be used. As can be seen, VCCT among other things can facilitate behavioural change, prevention of mother to child transmission (PMTCT), STI prevention and access to medical care and treatment. It provides tools for coping with a person's serostatus and has been shown to have a destigmatising effect.

VCCT and SRHR

By looking at the estimated number of PLWHA and comparing this with the currently available VCCT facilities, one realises that there is a severe service delivery gap. Furthermore, there is a bias towards urban areas when it comes to accessibility of services. However, this lack of service delivery is only part of the problem. As written in Chapter 3, stigma and discrimination against PLWHA is widespread and this is often a serious barrier limiting access to VCCT.

Box 20. Key principles of VCCT Services

Voluntary: Knowledge of HIV status is voluntary. The decision to have a test must be made by the client.

Confidential: Information shared during counselling must not be shared with others. The HIV test result must only be reported to the client unless the client states the desire to share the test result with a family member, partner or close friend.

Informed consent: The client agrees to HIV testing through giving their informed consent.

Privacy: The physical environment must allow private discussion between the client and counsellor. The service provider must keep clients' personal details private.

Source: IPPF and UNFPA (2004). "Integrating HIV Voluntary Counselling and Testing Services into Reproductive Health Settings".

As it is a challenge to "recruit" people for testing, it is important to introduce VCCT in health-care settings. Reproductive health-care settings are a good opportunity for integrating VCCT as topics such as sexuality and STIs often are dealt with in these settings. Furthermore, women in some regions make up more than half of the infected population but can be hard to reach through project interventions, due to their confinement to the private sphere. This is also a reason why it is important to integrate VCCT into reproductive health-care settings – a place that women occasionally do approach for antenatal care, family planning or STI treatment. Another advantage of integrated VCCT and reproductive health services is that people might perceive it as less stigmatising or as a way of avoiding stigmatisation completely to approach a more broad health-care facility compared to a stand-alone VCCT centre, as the surrounding community cannot judge the motive for visiting the facility.

However, avoiding stigma is not sufficient. Reducing stigma and discrimination in the family, community and at the workplace needs to be and should go hand in hand with VCCT interventions. The increased availability of ARVs has, in some countries, led to reduced stigmatisation, as medical treatment signals that AIDS is "just another disease". Some claim that the perspective of being able to obtain treatment makes people come forward for VCCT. However, free treatment is not always provided and as a result the potential of the link between VCCT and access to treatment is still not very clear.

Figure 1. HIV counselling and testing as an entry point for prevention, care and treatment of all people.

Source: Adapted from the WHO online VCT toolkit (http://who.arvkit.net/tc), Family Health International and UNAIDS.

VCCT and violence against women

After having undergone VCCT it is important that the test result, particularly if positive, is disclosed to the partner. However, disclosure of the test result is not easy. Many people, particularly women, might keep the fact that they have undergone testing a secret, as the decision to be tested is often perceived by the sexual partner as a sign of distrust and an acknowledgement of their own risky behaviour. As described in Chapter 8 on orphans and other vulnerable children, accusations on who brought the virus into the family can often be devastating. Many times women are threatened by their husbands or partners that they will abandon them and some women are severely beaten, particularly if found to be HIV positive. VCCT for couples has therefore been promoted as a way to prevent the frequent violence the women have to face. In many cases this has had a positive outcome. However, the situation is more challenging if only one of the couple tests positive for HIV.

■■■ Entry points for NGOs

■■ Interventions developed for HIV prevention in infants provide a unique opportunity to link HIV prevention with care and treatment services for HIV-infected women, infants and other family members. Such interventions are an important entry point for the provision of quality care and treatment, including ART. In the current context of increased access to ART, the vast majority of HIV-infected women and their infants who are in need of ART

Resources

- **IPPF and UNFPA (2004). "Integrating HIV Voluntary Counselling and Testing Services into Reproductive Health Settings" (www.ippf.org)**

This guide provides stepwise guidelines for programme planners, managers and service providers. It emphasises that the benefits of integration include increased access to services for people wishing to know their HIV status; opportunities for providing SRH care to groups such as young people and men who might not otherwise access such services; and the potential for saving costs due to similarities in infrastructure and core skills between VCCT and SRH programmes. Challenges are also identified, including the perception that service quality has suffered because of integration; the stigma against HIV testing; and the possible strain on financial and human resources.

Box 21. Training VCCT counsellors

The Danish Mission Council Development Department has experience with projects in Botswana and Liberia, where churches have trained laypeople in counselling and established VCCT centres. In order to be able to provide qualified counselling, emphasis has been put on the training of the counsellors, which includes six weeks training and around six months of fieldwork, where the counsellors have to pass a practical exam and write a case study over ten counselling sessions. For the success of projects it has been extremely important that the counsellors are well equipped to tackle the many different cases they may face.

In Botswana the health system is aware of the hospitals' limited resources for offering proper counselling. Therefore, some of the hospitals work closely together with the doctors from the VCCT centre, and health workers refer clients to the laypeople counsellors for pre and post-test counselling. The advantage of using laypeople as counsellors is the ability for them to follow up on the clients after they have been discharged from the hospital and by home visits. In this way, the counsellors seek to involve the entire family, and a preventive effect on especially the young generation in the family has been observed. This intervention also seems to reduce the stigma in the family and the community. The family is helped to understand the nature of the sickness and the client is supported in talking openly about his or her status.

It has been experienced that people are less likely to change behaviour and attitudes by attending workshops and awareness campaigns about HIV/AIDS than when a counsellor sits under a tree and talks about the clients own life in their own context.

- **UNAIDS. UNAIDS Global Reference Group on HIV/AIDS and Human Rights (www.unaids.org/en/in+focus/hiv_aids_human_rights/reference+group.asp)**

The Global Reference Group has addressed in detail current debates on HIV testing and counselling. There are more than ten important documents on this website addressing issues such as the key elements of testing (included informed consent), HIV testing of specific populations (such as young people) and the human rights implications of HIV testing.

- **Maman S et al (2001). "HIV & Partner Violence: Implications for HIV Voluntary Counseling & Testing (VCT) Programmes" (www.popcouncil.org/horizons/ressum/vct_violence.html)**

A key part of VCT programmes is encouraging the disclosure of test results to partners. Does the fear of violence inhibit women from telling their partners their serostatus, and do women experience violence when they do reveal test results? A study undertaken in Tanzania examines these issues.

will be identified through PMTCT;

- Integration of VCCT in reproductive health services such as antenatal care or family planning services;

- In family planning clinics, condoms can be promoted as protection against unwanted pregnancies as well as HIV;

- NGOs can play a leading role in promoting and advocating for the rights of women from the community to the government level. □

18. Community home-based care

Due to the increasing number of people living with HIV/AIDS (PLWHA) and the inability of health-care systems to attend to them, there is an expanding need for home-based care and treatment of those suffering from non-fatal complications of the disease. Their numbers are so large that hospitals cannot accommodate them. However, comprehensive care, which aims at linking a network of providers and services to comprehensively address the needs of PLWHA and their caregivers, should include referrals between home or community and the hospital and vice versa. To the extent possible, the approach should consist of four interrelated elements:

- Clinical management, including early diagnosis and treatment of opportunistic infections;
- Nursing care to promote and maintain hygiene, nutrition and infection control, to provide palliative care and health education to home carers;
- Counselling, including psychosocial support to PLWHA and their families, to reduce stress and anxiety, to promote positive living and risk reduction strategies, and to empower individuals to make informed choices for their futures;
- Social support, including material assistance, information and referral, linking into support groups and services.

Nursing care, counselling and social support are areas addressed through community home-based care (CHBC). According to the International Federation of Red Cross and Red Crescent Societies, the main objective of HIV/AIDS related home-based care is to "improve the quality of life and survival of PLWHA and to maintain their dignity. It also aims to contribute to the reduction of stigma and discrimination against PLWHA and the further spread of the virus, and so reduce the impact of HIV/AIDS on individuals, families and communities". However, it is important to acknowledge that CHBC in practice can increase stigma, particularly if there is an insufficient stakeholder consultation at the community level

Table 1. Essential elements in CHBC

Category	Subcategory
Provision of care	Basic physical care. Palliative care. Psychosocial support and counselling. Care of affected and infected children.
Continuum of care	Accessibility. Continuity of care. Knowledge of community resources. Accessing other forms of community care. Community coordination. Record-keeping for ill people. Case-finding. Case management.
Education	Curriculum development. Educational management and curriculum delivery. Outreach. Education to reduce stigma. Mass media involvement. Evaluation of education.
Supplies & equipment	Location of the CHBC team. Health centre supplies. Management, monitoring and record-keeping. Home-based care kits.
Staffing	Supervising & coordinating CHBC. Recruitment. Retaining staff.

Financing and sustainability	Budget and finance management. Technical support. Community funding. Encouraging volunteers. Pooling resources. Out-of-pocket payments. Free services.
Monitoring and evaluation	Quality assurance. Quality of care indicators. Monitoring and supervision. Informal evaluation. Formal evaluation. Flexibility.

Source: WHO (2002). Community Home-Based Care in resource-limited settings – a framework for action

The table above summarises the main components of CHBC. The first category concerning the provision of care is particularly important for PLWHA. Provision of care includes the following areas:

- Basic physical care, which includes cleaning wounds, bathing, support to get an adequate diet and relieving pain. This component could also include ensuring that PLWHA receive their ARVs regularly and continue to take their medications as prescribed;
- Palliative and terminal care, which aims at providing physical support including pain relief, as well as providing support in covering the psychological, social and spiritual needs of ill people and caregivers;
- Psychosocial support and counselling is a very crucial element, as the mental health of ill people, family members and members of the CHBC team is vitally important. However, providing emotional support is very difficult for the caregivers if they do not feel cared for themselves;
- Care of affected and infected children, as they are often greatly affected by economic hardship, which often leads to malnutrition, prostitution, becoming street children or entering into early marriage. Furthermore, due to poverty, their own care burden (children headed households) or becoming orphaned, children often have to leave school.

Caregivers

Caregivers can be many different people all according to the environment of the PLWHA. Often, the primary caregiver is a family member, either mothers or grandmothers. In sub-Saharan Africa, AIDS is sometimes referred to as the "grandmother disease", as grandmothers are the ones left in villages to care for

Box 22. CHBC: The Danish Red Cross in Ethiopia

In 1999, the Danish Red Cross supported the piloting of a CHBC project in Tigray, Ethiopia. The objective of the project was to build the capacity of families and communities to provide care and support to PLWHA and their families. As the Red Cross is based on a strong volunteer network, the project included the training of volunteers for three days in home-based care. The training included basic facts on HIV and AIDS, prevention of HIV infection, care for PLWHA (first-aid, stress management and more basic clinical care) and counselling and referral.

In addition, family members of PLWHA, community members, young people, community leaders and PLWHA were trained for six days in awareness creation, HIV prevention and simple home-based care for PLWHA.

The Red Cross volunteers provided nursing care and psychosocial support for the PLWHA during home visits and assisted the clients during referral for further treatment to the health facility.

Source: International Federation of Red Cross and Red Crescent Societies, 2003: "Community home-based care for people living with HIV/AIDS – The Ethiopian Red Cross Society Tigray Branch, Lessons learnt and the way forward"

Resources

- **WHO (2002). Community Home-Based Care in Resource-Limited Settings: A Framework for Action (www.who.int/hiv/pub/prev_care/isbn9241562137.pdf)**

This document provides a systematic framework for establishing and maintaining community home-based care in resource-limited settings for people with HIV/AIDS and those with other chronic or disabling conditions. There is an extensive list of resources at the end of this publication.

- **National AIDS/STD Control Programme, Kenya (2002). "National Home-Based Care Programme And Service Guidelines (www.policyproject.com/pubs/policyplan/KEN_HBCPS.pdf)**

Although focused on Kenya, the National Home-Based Care Programme and Service Guidelines have general relevance as they spell out the basic components of home care services, the programmatic standards, and the requirements for service delivery.

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both victims of AIDS and their children, who may also be victims of the disease. However, it also often happens that children become the primary caregivers of their parents, something which is often not sufficiently acknowledged (read more in Chapter 8).

Apart from family members, there are two categories of caregivers which are frequently used: informal and formal. The informal category includes friends, neighbours and in some cases also members of the church. As described in Chapter 19 on tuberculosis, the so-called "accompagnateurs", laypeople that provide social support to patients, have shown to be a valuable resource for HIV-positive patients in Haiti. The formal caregivers are people who have been recruited and trained by CHBC programmes or otherwise. Involvement of PLWHA among the formal caregivers on the CHBC teams is important as they will be able to provide psychosocial support as well as support to other PLWHA.

One of the great challenges of CHBC programmes is to ensure that the informal as well as the formal caregivers do not burn out. Taking care of a PLWHA is a draining task, and providing psychosocial support to the caregivers is vital.

■■■ Entry points for NGOs

■■ Providing care for the caregivers by ensuring proper training, monitoring and compensation for the voluntary staff. Many lessons from the work with peer educators in reproductive health programmes can be used;

■■ Providing care for the caregivers by ensuring proper training, Anti-stigma and discrimination programmes addressing CHBC at the community level;

■■ Training of men in their capacity as father and partners at the household level to make them understand the importance of care giving at home. ☐

19. Tuberculosis

One of the most common opportunistic infections that HIV-infected people get, due to their decreased immune response, is pulmonary tuberculosis (TB). This has led to an upsurge of TB cases in the world, and in many countries of sub-Saharan Africa a large proportion of hospital beds are used by patients with both HIV and pulmonary tuberculosis. In spite of being a curable disease, TB still threatens the lives of the family, friends and neighbours of those infected.

Normally, TB is not difficult to treat. After diagnosis (e.g. by sputum smear microscopy of what is coughed up), the treatment entails some months of an oral combination treatment. The big problem is to get people with TB to complete the full treatment. If it is interrupted prematurely, partially or completely, the TB bacteria that are still in the body become resistant to common medicines. Drug-resistant TB is rapidly increasing due to the failure of many people to complete the required treatment.

The global answer is a campaign called “Stop TB”, which as its main intervention has the DOTS strategy. This strategy has five components:

1. sustained political commitment;
2. access to quality assured TB sputum microscopy;
3. standardised short-course chemotherapy to all cases under proper case-management conditions including direct observation of treatment;
4. an uninterrupted supply of quality-assured drugs;
5. a recording and reporting system that will enable an outcome assessment.

The TB case management component often builds on the agreement with people in the social network of the identified TB patient so that someone can be appointed to help ensure that the full treatment is completed by the patient. The local schoolteacher, minister, village elder or a family member, for example, can act as the person that literally monitors (direct observation) that the tablets are taken. This approach is very promising, and clearly builds on the work of civil society – the health sector alone cannot solve the global TB problem.

Another problem is that some people with pulmonary TB and HIV live destitute lives, e.g. as homeless, drug addicts or recently released prisoners. Here, it has sometimes proven beneficial to provide incentives and support such as food packages and transport vouchers in connection with the taking of the prescribed DOTS treatment. Food can be a good incentive for destitute people, and improved nutrition helps combat the TB in the body.

DOTS as a model for AIDS treatment: DOTS-HAART

The DOTS strategy has not only proven to be effective for controlling TB, but also an inspiration for preventing and controlling HIV/AIDS. TB and AIDS share many features in the sense that they are both infectious diseases that primarily attack poor people and that the treatment for both requires the regular uptake of pills over an extensive period of time. But whereas TB drugs have been available for a long time, antiretroviral drugs have only recently become available in low-income countries. Effective ways to deliver antiretroviral therapy are still under evaluation.

One aspect of the DOTS programme that has been tested by NGOs specialised in AIDS is the use of a so-called “accompagnanteur”. In Haiti, Partners in Health (PIH) and its Haitian sister organisation, Zanmi Lasante, have, since 1989, developed new methods to channel ARVs to people in very resource-poor, rural settings through a corps of acompagnateurs, laypeople who observe that the patient takes the prescribed pills. They respond to the concerns of the patient and the family and they provide psycho-social support. They are not volunteers as they receive a salary for their services and must undergo a programme of basic training. The accompagnateur is an important help to the physicians and nurses in their attempt to

Resources

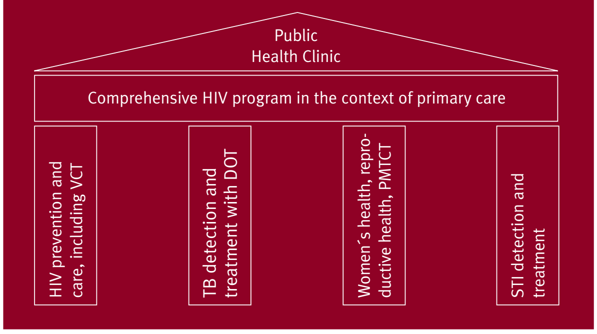
- **Partners in Health (July 2004). The PIH Guide to the 'Community-Based Treatment of HIV in Resource Poor Settings, XV International AIDS Conference, Bangkok Edition (www.pih.org/library/aids/PIH_HIV_Handbook_Bangkok_edition.pdf)**

This guide is intended to be a resource for physicians and other health-care professionals who provide care and treatment to patients with HIV in resource-poor settings. It draws on experience in Haiti, where Partners in Health has been providing antiretroviral therapy to patients with advanced AIDS since 1998. The guide reviews lessons learned from TB programmes and the use of the accompagnateur.

prevent drug resistance by ensuring the correct and consistent adherence to the programme. The "semi-professionalisation", although an additional cost, is also an advantage for the patient, who gets the right to choose his or her own accompagnateur based on personal preferences.

The use of accompagnateurs builds on lessons learned from TB programmes, suggesting that in situations of poverty, illiteracy and poor social support, patients may not take their medicines correctly, even if the pills are free. The "HIV Equity Initiative" in Haiti has shown that even in settings with a poor infrastructure, there might be a pool of underutilised social workers who, with basic training, can be involved in community-based programmes in a very efficient way. This initiative has therefore promoted a so-called DOTS-HAART approach where they attack these two infectious diseases in an integrated manner.

Figure 2. The Four Pillars of HIV Prevention and Care



Source: Partners in Health (July 2004). The PIH Guide to the 'Community-Based Treatment of HIV in Resource Poor Settings'.

Further lessons could be learned by NGOs from the DOTS strategy, such as organising an uninterrupted supply of quality-assured antiretroviral drugs and ensuring recording and reporting for treatment monitoring. Moreover, under the four interrelated pillars of AIDS prevention and care (see Figure 2), intersectoral collaboration is called upon to provide more effectively a package for prevention, care and support services for both HIV and TB.

■■■ Entry points for NGOs

■■Provide or promote integrated testing and care for TB and HIV/AIDS in the same health-care settings when possible and appropriate;

■■Support the development of local DOTS programmes, including the training of family members and others who can serve as "direct observers", ensuring that the treatment is taken;

■ **WHO Stop TB Department. (www.who.int/tb)**
This website provides a wealth of evidence and numerous documents on the DOTS strategy as well as linkages with HIV/AIDS, including the "Interim Policy on Collaborative TB/HIV Activities" (2004), Guidelines for implementing collaborative TB and HIV programme activities (2003) and Global Tuberculosis control - surveillance, planning and financing (2005).

■■ Provide incentives such as food, clothes or other support for participants in DOTS programmes;

■■ Help provide community support, including HIV testing and counselling, and home-based care for people with TB and HIV, and also help provide follow-up of people with HIV after they have completed the DOTS course of treatment;

■■ Help devise programmes that link newly arrived patients who are already in DOTS treatment – such as former prisoners leaving jails, refugees and drug users – with HIV counselling and testing centres, as many of them will also have HIV. ☐

Resources

- **UNAIDS (1997). Technical update: Blood safety and HIV and UNAIDS point of view: Blood safety and AIDS (www.unaids.org)**

The first of these two short documents address the three principal factors which contribute to an unsafe blood supply, particularly with regard to HIV: lack of safe donors and unsafe blood donations, lack of screening and blood used inappropriately or incorrectly. The second report focuses on how to ensure a safe blood supply.

- **Lackritz EM and McClelland B. "Ensuring the Safety of Blood and Blood Products". (www.fhi.org/en/HIVAIDS/pub/guide/HIVAIDSPreventionCare.htm)**

This resource is a chapter in HIV/AIDS Prevention and Care in Resource-Constrained Settings: A Handbook for the Design and Management of Programs, which offers state of the art knowledge on designing and managing HIV/AIDS programs.

20. Blood and injection safety

HIV transmission through blood or blood products has occurred repeatedly in well described instances during the evolution of HIV/AIDS. Haemophiliacs were among the first to contract HIV in the 1980s, before blood could be tested; in Europe there were scandals of HIV transmission even after routine testing was recommended; and most recently a large number of people in China have been infected. Transfusing infected blood or infected blood products does, unfortunately, carry a high risk of HIV transmission.

Much has been done in recent years to decrease the needs for blood and to avoid unnecessary transfusion. Still, life-saving blood and blood components remain irreplaceable in many clinical situations (maternal emergencies around birth, to accident victims with traumatic shock or to children with severe malarial anaemia). Testing for HIV/AIDS and other blood-borne infections is important and needs to be performed on each donation. However, testing does not fully guarantee that blood will be HIV free, as HIV-infected positive donations can not be identified during the window period. That is why the appropriate selection of donors is so important.

The safest donor is a voluntary and non-remunerated one, properly informed and with reliable low-risk behaviour. Donating blood by itself does not carry any HIV-related risks for the donor. Where donors are paid or otherwise remunerated, destitute people (e.g. the very poor or drug users) may sell their blood for survival. This should be avoided to the extent possible.

In many countries, the Red Cross and Red Crescent societies are responsible for organising the promotion of voluntary and safe blood donation, recruiting donors and carrying out donation campaigns and the like.

Earlier in the epidemic, when VCCT was even more difficult to access, blood bank services were sometimes used for getting free HIV tests, which increased the risk that unsafe blood could be transfused. This situation can still occur in some settings where VCCT services are either not appropriate (low confidentiality) or not sufficient.

Injection safety, disinfection and the safety of health workers

Procedures that penetrate skin with medical instruments ("invasive procedures") may risk transmitting HIV if the instrument happens to be contaminated with HIV. Vaccinations and other injections have been especially suspected for transmitting HIV, along with traditional procedures such as tattooing or scarification. Investigations have shown that many vaccinations and injections in low and middle-income countries – sometimes up to one-third of injections in certain settings – are performed in an unsafe manner.

As regards disinfection, it is well known that the HIV virus is very sensitive to many commonly used disinfectants. Once the

The handbook is intended to be used by programme mangers, technical and programmatic field staff, the staffs of donor and international partner agencies, health-care providers, and field researchers.

- **WHO. Universal Precautions, Including Injection Safety (www.who.int/hiv/topics/precautions/universal/en/)**

This WHO homepage provides all of the essential information on injection safety and provides references for further reading.

- **WHO. Blood safety home page (www.who.int/bloodsafety/en/)**

This WHO homepage provides all of the essential information on the blood transfusion chain, including safety requirements, and provides references for further reading.

right disinfectants are available, and the right cleaning method is employed, it is a simple procedure to clean health-care facilities, ensuring that blood and other bodily fluids that may contain HIV are fully removed.

In some countries with high HIV prevalence, some categories of health-care staff tend to leave the field of health care for fear of HIV transmission at the workplace. Such situations, coupled with losses caused by staff being ill with HIV-related infections, must be addressed by health-care planners. Apart from proper cleaning and disinfection, and strict and well implemented procedures for the handling of “sharps” e.g. disposal containers), one important measure to ensure staff safety is the provision of post-exposure prophylaxis with antiretroviral drugs for staff that accidentally have suffered from suspected exposure to HIV.

A major challenge in all health-care settings – in low, middle and high-income countries alike – is the implementation of safe universal precautions for health workers and patients. Disinfection of suspect body fluids, use of plastic gloves, hand-washing and the disposal of bodily material is vital. With regard to delivery, procedures such as routine cutting (episiotomy) should be discouraged, and health worker protection with aprons, gloves and eye-glasses encouraged.

Entry points for NGOs

- NGOs can contribute to promotional and educational campaigns for voluntary non-remunerated blood donation, which are run by the Red Cross/Red Crescent societies, donor associations or the government;

- Safe blood services test all blood for HIV (and for other defined infections). Post-test counselling for HIV-positive donors is an area where NGOs can be involved;

- Education to low-risk behaviour groups with regard to HIV and STI transmission should be part of information provided to young people and the general population for the promotion of voluntary, non-remunerated blood donation and this is an important entry point for NGOs;

- Contribute to injection safety, both when involved in various aspects of the provision of health care, including vaccination campaigns, and when contributing to population awareness;

- Contribute to safe disinfection procedures, both if the NGO takes part in health-care provision, and when contributing to population (client) awareness;

- Support health-care staff in the maintenance of safe routines for the handling of “sharps” and for the implementation of post-exposure prophylaxis with antiretroviral drugs when indicated.

Resources

- **UNAIDS (2000). Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa (www.hst.org.za/uploads/files/Collab_Lit_Rev.pdf)**

A background is given to the role that traditional medicine plays in HIV and health care generally in the region. Examples of collaboration are given and some reviewed according to UNAIDS best practice criteria (effectiveness, ethical soundness,

21. Traditional and other popular practices

Some traditional and some "modern", popular practices penetrate the skin and therefore carry the risk of HIV transmission. Certain traditional practices also increase the risk of sexual transmission. The most important of these practices are mentioned here.

While risky practices need to be either avoided or modified, their popularity also means that the provider of such practices – the traditional healer, the owner of the tattoo parlour and so on – has a potentially very important role in promoting safe practices. In a number of countries, traditional practitioners collaborate with the formal health system, in training and systematic dialogue, and are effective outreach agents promoting safer traditional and sexual practices. Both as regards female genital cutting and other traditional practices, they are potential health educators/promoters with regard to HIV/AIDS in general, as they often are respected individuals in their communities.

Female genital cutting

Among traditional practices, female genital cutting (FGC) is one that risks transmitting HIV from one girl to another if the cutting instrument is not sterilised. There is much community-based work to eliminate or reduce FGC, but such practices will likely be carried out for many years to come. Modifying the existing practice to reduce the risks of HIV transmission – as well as modifying the procedure towards less damaging types of FGC – requires close and culturally sensitive collaboration with the community. In this case it is often the female practitioners that are involved in the practice and who should be involved in discussions about constructive modifications.

Scarification tattooing, piercing and male circumcision

Skin-penetrating procedures imply a risk of HIV transmission if unclean instruments are used with multiple clients without proper cleaning or boiling. Some of the most common practices are:

- Scarification, which is the treatment of ailments by making wounds/scars close to the ailing body part, and often applying traditional ointments or herbs;
- Tattooing may be carried out for embellishment, sometimes as a traditional "rite de passage" in connection with puberty in girls, and today often among youth in general;
- Body piercing is a common practice both in "modern" and "traditional" societies;
- Male circumcision, usually in boyhood (more rarely in infancy) is also carried out by traditional practitioners in many communities.

efficiency, sustainability and soundness).

- **Richter R, AIDS Law Project (2003). Traditional Medicines and Traditional Healers in South Africa - Discussion Document (www.tac.org.za/Documents/ResearchPapers/Traditional_Medicine_briefing.pdf)**

This paper sketches a background of traditional healing in South Africa and discusses international policies, guidlines and the South African legal framework on traditional health practitioners. It argues that traditional healers can support the national response to HIV/AIDS and that there should be regulation of traditional healers and traditional medicine, as well as for the application of human rights principles within the traditional healing profession. The paper concludes with advocacy strategies and ways of aligning traditional healing with a human rights framework.

Vaginal dryness

Some traditional practices have more direct bearings on the sexual act or sexual encounter. One such practice is the widely used and varied methods of causing vaginal dryness. The intention of such practices is to increase vaginal friction during sexual intercourse in order to increase male sexual pleasure. This practice increases the risk of small lesions in the vaginal lining, and such microscopic damage to the vaginal wall in turn increases the risk of HIV transmission.

There are other sexual practices that also are detrimental for women's health, from an HIV perspective. It is extremely worrying that the female proportion of newly HIV-infected in sub-Saharan Africa is increasing, and in some countries is over 60% of new cases. The traditional practices in most cases contribute to this increase in morbidity among women, and other reasons are explained e.g. in Chapter 7 on sexual coercion and violence.

The positive potential of traditional providers

In poor countries with weak health systems, many people – perhaps most – tend to go to traditional health-care providers. They are often well respected and knowledgeable. In some countries, they are even registered and licensed. When recruiting the support of these esteemed traditional providers, one should remember that they are basically "private practitioners" working on a fee-for-service basis. Efforts by NGOs and others to modify traditional practices should take this into account in pre-project preparatory consultations with traditional practitioners.

Entry points for NGOs

While NGOs' approaches to modifying or reducing the use of various traditional practices will differ, there are some commonalities as regards entry points:

- Traditional and modern practitioners, and if necessary religious leaders, should all be involved in setting goals and planning strategies for change;

- Be brokers between networks of traditional practitioners and the public authorities, including public health authorities;

- In advocacy efforts, highlight the gender aspects of traditional practices when relevant.

Resources

- **Green A (1999). An Introduction to Health Planning in Developing Countries. Oxford University Press.**

This comprehensive book is aimed at planners and health policy-makers involved in planning for health in developing countries. The key concepts and techniques of each of the stages in the planning spiral (figure 3), from the situational analysis to evaluation, are explained in individual chapters. The book concludes with an analysis of why planning has not always been successful and discusses how it can be strengthened. In addition to the main text, the book also contains a number of exercises to practice techniques, an extensive bibliography and a list of key websites.

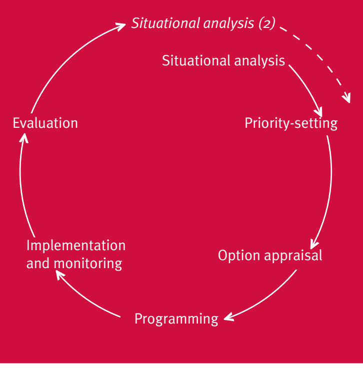
22. District health planning

Ideally, planning for HIV/AIDS in a district is a concern for all sectors, and the work is led by the leadership team of the district. However, this is not always the case and the health sector may be in a position to take the initiative for overall HIV/AIDS planning. The health sector often has the best possibility to assess the HIV/AIDS situation in the district, can assist in projections and as a result help predict what needs will arise in different sectors due to HIV/AIDS. Given the often overburdened situation of the health sector, isolated planning in this sector will usually mean emphasising care-related issues at the expense of paying sufficient attention to broader preventive measures in society. The chapter on district planning addresses ways of planning broader, such as involving other sectors and NGOs.

In the health sector itself, a range of different needs arise due to the HIV/AIDS pandemic. Planning how to meet those needs must be incorporated into the regular planning cycle. “The planning spiral” is typically a generic process that includes the following steps:

1. assessment – assessing major (health) problems and the current efforts to address them (ongoing interventions, resources including staff, funds and infrastructure);

Figure 3. The planning spiral



Source: Green A (1999). An Introduction to Health Planning in Developing Countries. Oxford University Press.

- **EQUINET (Network for Equity in Health in Southern Africa).**
  ART treatment access and effective responses to HIV and AIDS: providing new momentum for accessible, effective and sustainable health systems
  (www.equinetafrica.org/bibl/docs/treatment%20access.pdf)

This briefing outlines the major findings and issues from work carried out in southern Africa on equity in health sector responses to HIV and AIDS, particularly in terms of access to antiretroviral treatment. It presents options drawn from the evidence and experience in the region on how to strengthen equity and include low-income or more vulnerable communities in treatment access programmes. Reaching through district services to primary care levels is described as one of the main effective responses to AIDS.

- **DFID Health Systems Resource Centre (2002).**
  Allocating public resources for health: developing pro-poor approaches (www.dfidhealthrc.org/shared/publications/Issues_papers/Allocating_resources_final.pdf)

This issues paper addresses how financing policies be made more pro poor, focusing on the allocation of public resources and the extent to which different approaches enable poor people to access essential services. It provides examples from district level planning in Cambodia, South Africa and Uganda.

2. stakeholder consultation – systematic consulting with the stakeholders on the major issues to hear their views on both the current (health) problems and the ongoing efforts to resolve them;

3. options appraisal – listing the major options for intervention for the next 1-2 planning cycles and appraising them. Some issues to be considered are: What is realistic or most effective, and which intersectoral efforts require support?;

4. prioritisation – within the district team, prioritising and gradually selecting the major thrusts for the next planning cycle (2-3 years);

5. detailed planning and budgeting – mapping out the activities in a chronogram, detailing the persons responsible, budget lines and monitoring indicators and "milestones", i.e. major activities;

6. implementation – actually carrying out the activities planned over the 2-3-year period;

7. monitoring – keeping track of the activities being implemented, including the milestones;

8. evaluation – carrying out an evaluation to assess what was achieved at the end of the planning cycle;

Box 23. Select health sector components related to HIV/AIDS

I. Outreach activities to communities
  1. Community-based preventive activities
  2. Support for home-based care

II. Outpatient services
  1. Voluntary confidential counselling and testing
  2. Provision of antiretroviral therapy
  3. Tuberculosis services (e.g. DOTS)
  4. STI services
  5. Family planning services
  6. Maternal health care services
  7. Youth friendly health services

III. Hospital/inpatient services
  1. Blood banks
  2. Inpatient care

9. new assessment – assessing major (health) problems and current efforts to meet those needs and what is additionally required.

With a growing pandemic, no area of the health sector is spared. The parts of the health sector that need special attention due to HIV/AIDS are listed in Box 23 (details of many of them are dealt with in separate sections of this manual). The full list is long as it reflects what happens in the health sector when e.g. 10-30% of the population is infected with HIV and people with AIDS and AIDS-related illnesses seek help and care in the health sector. It is easy to see how the growing burden on inpatient services easily can swallow most of the resources appropriated to health care, if conscious choices are not made to also support preventive activities such as family planning, youth-friendly reproductive health services and harm reduction. Both community organisations, non-profit NGOs and private for-profit partners working in health are all important in trying to balance the priorities when planning for an overburdened and underfinanced health sector.

■■■ Entry points for NGOs

■■ NGOs can contribute to the planning process of the district health authorities with their local, national or international experiences;

■■ NGOs can help facilitate the district level planning process in the health sector and potentially also in other sectors, depending on their local role. Locally active NGOs constitute local stakeholders;

■■ NGOs can be subcontracted by the public health authorities to implement certain parts of the district health plan where relevant. □

Taking the next steps

The six chapters in this section are:

Whereas the previous chapters treated specific, often technical, topics related to HIV/AIDS, the next chapters address what can be done by NGOs and their partners.

This section moves one step ahead by discussing the very central role that NGOs play, be they specialised in HIV/AIDS work or oriented towards general health activities. The different chapters review common entry points and participatory approaches for NGOs to address in relation to the integration of sexual and reproductive health in HIV/AIDS, and end by considering advocacy, training and monitoring and evaluation.

23. Common entry points for NGO projects to address HIV/AIDS and SRHR

Although HIV/AIDS and SRHR influence each other in a variety of ways, there has, to date, been very little common ground for both preventing HIV/AIDS and promoting SRHR. Traditionally, HIV/AIDS prevention and care and SRHR services (or even family planning (FP) alone) have been carried out through separate, vertical services. FP services have targeted married women of reproductive age, while HIV/AIDS services, on the other hand, have aimed at reaching so-called high-risk groups, e.g. commercial sex workers, injection drug users and other individuals that were, often wrongly, assumed not to have reproductive health needs of their own. However, in many countries the epidemic has quickly moved into the general population with the result that a growing number of women of reproductive age become HIV positive, and the understanding of the sexual and reproductive needs of people at high risk of HIV infection grows. It is evident that the different factors related to HIV and SRHR should not be addressed piecemeal but in combination. There is, therefore, an immediate need for identifying common entry points for NGOs in order to improve the integration of services and other project activities.

This chapter addresses integration inside as well as outside the health sector: (i) what kind of analysis is required to decide whether HIV/AIDS should be integrated into existing FP services or whether it should be the other way around; (ii) operational definitions of integration in health-care settings as well as in social work and in advocacy; and (iii) examples of concrete types of integration in health services. The comparative advantage of NGOs often lies in their ability to operate outside the health sector by using advocacy at the policy level and behaviour change communication at the community level. NGOs should therefore not restrict themselves to provision of health services.

Identifying common entry points for the integration of activities

The success of any project response depends on the clarity of the analysis and the quality of the strategic thinking and networking that precede the project initiation. This is especially true for the identification of common ground for HIV/AIDS and SRHR. All communities do not require the same kind of AIDS control programmes. Communities with generalised HIV and STI epidemics need one kind of programme, while those with low HIV and STI prevalence require another type.

The choice of approach should be based on a thorough situation analysis, including a stakeholder analysis, in which the views of all actors and other stakeholders are taken into account. A situation analysis should cover: (i) a fine-tuned, epidemiological analysis identifying the groups with a high risk of HIV infection; and (ii) a socio-economic and anthropological mapping of the situations and the contexts that are most likely to expose them to risk. An example of the latter could be a community where sexually active young women are more concerned about the risk of unwanted pregnancies than that of HIV infection. This being so, they will not be receptive to HIV prevention messages because the virus will be perceived as a distant threat. They are, on the other hand, far more likely to be interested in information about contraceptives.

Consequently, they should be informed about condoms as a method of dual protection against pregnancy and STIs/HIV.

Whereas the first analysis can be illustrated by the matrix in Table 2, the second requires an analysis of the relationships between the direct and indirect underlying causes of risk and vulnerability that cannot be encapsulated in a matrix.

The matrix suggests that full integration of reproductive health services and an HIV/AIDS package is most relevant, and cost-effective, in countries where the HIV epidemic has become generalised to the extent that more than one per cent of pregnant women have become infected. In those countries, large population groups are likely to need family planning advice and HIV prevention simultaneously and it would be unethical not to offer both. On the other hand, in countries where the HIV epidemic is relatively high yet contained within certain subgroups of the population, project efforts and funds should be earmarked to sexual and reproductive health services for the general population and specific HIV and family planning interventions for the at-risk subgroups. Finally, in countries where the HIV epidemic is relatively low within high- risk groups and even lower in the general population, HIV/AIDS interventions should be mainstreamed into existing reproductive health services.

Table 2. Appropriate services by type of HIV epidemic

HIV epidemic type	Service for type & population
Generalised: Prevalence above 1 per cent among pregnant women	Integrated family planning HIV (FP)/HIV packages for general population and high-risk populations
Concentrated: HIV prevalence above 5 per cent in at least one at-risk sub-population but below 1 per cent among pregnant women	FP for general population HIV prevention (and possibly FP) for high-risk populations
Low level: HIV prevalence below 5 per-cent in at-risk subpopulations and below 1 per cent among pregnant women	FP for general population HIV packages for high-risk populations

Source: Adapted from U.S. Agency for International Development (USAID), 2003. Family Planning/HIV Integration: Technical Guidance for USAID-Supported Field Programs. Washington, DC, USAID.

Obviously, it is important to follow epidemiological developments closely to facilitate the swift adaptation of interventions. NGOs should ask for regular epidemiological updates from the national statistics bureau or other services to keep themselves abreast of the situation.

Defining meaningful integration

Within the health-care system, integration of services can be defined as the offering of at least two services at the same health facility during the same opening hours. Service providers should actively invite, but not push, clients to use some of the related services that they might not initially be aware of. For example, a man with unknown HIV status who is seeking advice for sexual dysfunction or treatment of an STI could be encouraged to attend HIV-related sexual risk reduction counselling. Another example could be an HIV positive woman attending a session on childbirth and breastfeeding; she should be considered for cervical cancer screening because HIV-positive women risk contracting this type of cancer at a younger age than women who are HIV negative.

In cases where it is not convenient or possible to offer SRHR and HIV/AIDS services in the same facility, a strong and systematic referral system can also qualify as integration of services. Sexual and reproductive health services would typically include FP, screening and treatment for reproductive tract infections (RTIs) and sexually transmitted infections (STIs), antenatal care (ANC), post-abortion care and other services. The HIV/AIDS package would then typically include prevention, care and treatment through voluntary confidential counselling and testing (VCCT), condom distribution, prevention of mother-to-child-transmission (PMTCT), treatment of opportunistic infections (OI) and possibly antiretroviral treatment. See Chapter 13 for more information on FP, Chapter 16 on STIs, and Chapter 17 on VCCT.

Outside the health-care system, NGOs have great potential for

Resources

- **EngenderHealth. Integration of HIV Prevention and Care. (www.engenderhealth.org/res/onc/hiv/index.html)**

This mini-course is designed to provide a basic introduction to the topic and help providers of reproductive health services incorporate a focus on HIV and AIDS into their services.

- **Countdown 2015 (2004). Can This Marriage Work? Linking the response to AIDS with sexual and reproductive health and rights. (www.countdown2015.org)**

This article is one in a compilation of many articles on sexual and reproductive health and rights. "Countdown 2015: Sexual and Reproductive Health and Rights for All" is an initiative of civil society organisations and works to assess the progress and map the future for the key goals of the International Conference on Population and Development. The Countdown 2015 magazine and other resources of the website also address aspects of gender and HIV/AIDS.

- **Pathfinder (2005). Integrating SRH and HIV/AIDS Services: Pathfinder International's Experience Synergizing Health Initiatives (www.pathfind.org)**

This document provides a brief background on integration, followed by programme descriptions of Pathfinder's integrated

influencing the underlying causes that contribute to poor sexual health and the spread of HIV/AIDS. In order to identify how to operate outside the health-care system, NGOs should start by defining which stakeholders are the most influential "mediators" on sexual and reproductive practices, e.g. peers, parents, the mass media, religious leaders or traditional healers as well as the relevant "spaces" outside the health-care sector where information should be made available, e.g. youth clubs, brothels, truck stops, schools and workplaces. Information and education can be integrated through campaigns, peer education, behaviour change communication, community outreach and home-based care that build on the relation between sexual and reproductive health and HIV/AIDS. These kinds of communication activities should, as mentioned above, be based on problems identified by the target groups themselves, be they unwanted pregnancies, child health, violence or food insecurity, and then be put into an SRHR and HIV/AIDS perspective in an appropriate manner by the NGO. Such a strategy should build on partnerships with the most important stakeholders.

Advocacy is another area where SRHR and AIDS messages should be combined, especially in countries with a high prevalence of HIV. Decision-makers must understand the interlinkages between them and the underlying causes that promote ill sexual health as well as the spread of HIV. The SRHR community can learn much from the AIDS agenda. International AIDS advocates and NGOs have succeeded in establishing a strong and vocal constituency for access to treatment whereas the constituency for the right to even basic prevention services is less visible and not nearly as successful. Yet, it is the same health-care system that will have to respond to both HIV/AIDS and ill sexual and reproductive health. The advocacy message should be that to address either one of them, policy-makers need to understand both. Advocacy must therefore go beyond "messaging"; it must set agendas, bring issues into the public sphere, articulate debates and ultimately influence legal frameworks, service infrastructure and a broader range of policy-making.

Different types of integration: how to integrate services

There are a number of common entry points for integrating health-care-based services. The choice of approach must depend on the epidemiological situation and the comparative advantages of the NGOs involved in the work. When necessary, projects worldwide. Different integration strategies and experiences are explored, including the integration of FP/SRH services into HIV/AIDS care and support services, as well as integration of HIV/AIDS into FP/SRH services for youth and vulnerable populations, and concludes with a synthesis of lessons learned and challenges that remain in integration.

- **UNFPA (2003). Preventing HIV Infection, Promoting (www.unfpa.org/upload/lib_pub_file/204_filename_ preventing-hiv-eng.pdf)**

This annual publication provides information about actions taken by UNFPA, the United Nations Population Fund, to prevent HIV infection. Global, regional and country examples provide insight into the types of HIV prevention activities that NGOs can become involved in.

- **Family Planning International (2004). Integrating Services in network, Vol. 23(3)**

(www.fhi.org/en/RH/Pubs/Network/v23_3/index.htm)

This issue of Network, an overview of current thinking about integration, is the first of a series of publications intended to encourage health professionals to ask questions or share their experiences of service integration.

Table 3. Addding family planning to VCT: levels of integration in Kenya

Level	Services Provided	Requirements
I	▪ Assessment of pregnancy and STI risks ▪ Information and counseling on methods ▪ Provision of condoms and pills ▪ Referral for other methods	▪ Minimal training of counselors to provide services ▪ Availability of job aids, condoms, and pills ▪ Time and space to provide services
II	▪ All services in level I ▪ Provision of injectables	▪ All requirements in level I ▪ Counselors trained to provide injectables ▪ Adequate infection-control procedures in place ▪ Additional equipment and supplies
III	▪ All services in level II ▪ Provision of IUDs	▪ All requirements in level II ▪ Counselors trained to provide IUDs ▪ Additional equipment and supplies
IV	▪ All services in level III ▪ Provision of full range of methods	▪ All requirements in level III ▪ Medical doctor to perform surgical procedures ▪ Additional equipment and supplies

Note: IUD = Intrauterine device; STI = Sexually transmitted infection; VCT = Voluntary counselling and testing
Source: Kenya Ministry of Health. Strategy for the Integration of HIV Voluntary Counseling and Testing Services and Family Planning Services. Nairobi, Kenya: National AIDS and STD Control Program and Division of Reproductive Health, 2004

they must be willing to supplement their work with others who can provide additional expertise. Table 3 offers an example of how the Kenyan Ministry of Health has worked with common entry points for FP and VCCT.

- HIV/AIDS and STI prevention integrated into FP clinics (or outreach activities), mother and child health, or antenatal care

This kind of integration is increasingly common because it allows a large number of people to be reached at the same time by the same providers. In this way, NGOs can respond to a variety of needs while providing a higher degree of convenience to clients. It is in particular an excellent opportunity to reach married women who risk getting HIV from their partner and who would not otherwise actively seek HIV advice. To have a minimum standard of quality, the providers need to be trained on sexual relationships, gender issues and domestic and related violence.

- VCCT integrated into FP or ANC

Although not yet that common, this kind of entry point is on the rise. The potential benefit is that it will increase the access to and use of VCCT and at the same time increase the awareness of sexual practices because the people who attend FP or ANC clinics are already sexually active. It can also reduce the number of HIV-infected births by either helping HIV-positive women to avoid unwanted pregnancies or by offering PMTCT to those who wish to give birth. In this case, the providers who are accustomed to solely offering FP and ANC services need special training on HIV/AIDS, patient confidentiality and on attitudes towards stigma and discrimination.

- FP integrated into VCCT

This kind of integration is still limited but is becoming increasingly common. Men and young people, especially if they are unmarried, are more likely to visit a VCCT clinic than a traditional FP clinic. To be able to offer counselling on contraceptives, in addition to HIV testing, is an important opportunity to promote dual protection via male and female condoms coupled with another form of contraception, e.g. oral contraception. (See Table 3. for an example of this kind of approach).

■■■ Entry points for NGOs

■■Conduct epidemiological, socio-economic and anthropological analyses of the HIV/AIDS and reproductive health situation in the project area on a regular basis in order to determine what kind of services are most appropriate;

■■Identify your own institution's field of expertise and establish functional partnerships with specialised services in the area that can be used for referral where your own expertise is insufficient to offer integrated services;

■■Strengthen the crossover skills of NGO staff by encouraging AIDS specialists and reproductive-health-specialised staff to attend each other's meetings and workshops and to read each other's journals to increase mutual understanding;

■■When you decide to integrate services, ensure that service providers possess the required skills, equipment and supplies by adapting training programmes, supervision and evaluation accordingly. □

24. Working together – participatory approaches

Partnerships and participation are some of the entry points to the fight against HIV/AIDS that most NGOs agree on. But why partner? First of all, because partnerships ideally bring together different organisations with diverse expertise and experiences. Secondly, because formalised partnerships – as opposed to informally constituted networks – potentially provide the basis for co-ordinated action in an accountable manner and can foster more creative and debated responses to the problems related to HIV/AIDS and SRHR. Finally, the combination of diversity and a common purpose offers an excellent platform for advocacy. Yet, partnerships without adequate involvement of the concerned stakeholders soon become irrelevant. This chapter therefore addresses the crucial participation of PLWHA in any kind of partnership between organisations.

Partnership typologies

For simplicity, partnerships can be categorised in three generic types:

1. between like-minded organisations;
2. between qualitatively different organisations; and
3. between unlikely partners.

Partnerships among like-minded organisations are characterised by member organisations that to a certain degree share the same overall goal and that might have developed a tradition of working together. There are many successful examples of this type of partnership because they are relatively easy to establish and maintain. Alternatively, partnerships can arise between widely different organisations, such as between a research institution that brings academic experience with research methodologies into the partnership and an NGO a sense of emerging issues that are relevant to the stakeholders. This type of partnership demands a higher degree of investment because it necessitates the establishment of new collaboration methods for both partners. Finally, partnerships can exist between unlikely partners, for example an NGO that collaborates with private business enterprises, the Soroptimists or the Freemasons for example. This type of partnership entails great challenges due to the partners' fundamental differences in vision, values and structure; but it also offers a potential for important and unexpected results. An NGO may gain access to a target group of decision-makers that would otherwise be hard to reach with HIV/AIDS and SRHR advocacy messages.

How to overcome barriers to an equal partnership

Partnerships can be between organisations based in high-income countries, between high, middle and low-income countries or in low-income countries alone. But they must involve a minimum of two organisations. Partnerships in low-income countries alone are particularly interesting because they constitute a step on the way towards self-sufficiency and internal capacity development and should therefore be encouraged. The will and ability of NGOs to establish solid partnerships with civil society organisations are particularly important in the spheres of HIV/AIDS and reproductive health because such partnerships may establish an interface between the health system and the user. A large percentage of HIV/AIDS health-related care and treatment is faith-based and it would therefore be useful for NGOs that do AIDS work or that wish to integrate AIDS work in their existing programmes to establish functional work relations with the relevant religious organisations.

But partnerships between different organisations are not always easy. Conflicts can arise if roles and responsibilities are not clearly defined, if the sharing of resources is not fair or considered to be fair, or if the division of leadership is unclear.

These potential sources of conflict and tension can be prevented if the following pieces of advice are considered:

- Develop trust across organisational boundaries and "business cultures" through formal and informal interaction. This trust is based on respect for the contribution of all partners;
- Become familiar with each other's language, experience and expertise through step-by-step up-scaling of the collaboration;
- Discuss objectives, expectations and requirements of individuals and organisations beforehand with all the involved partners (e.g. managers, technical staff and administration);
- Establish common grounds of interests and mutual benefit for all involved organisations;
- Set up flexible monitoring mechanisms that can grasp and document expected and unexpected outcomes of the collaboration;
- Invest sufficient time, energy and good will in the collaboration; and
- Establish feedback mechanisms to ensure that the benefits of the collaboration are shared systematically with everybody in the organisation and not just among those directly involved.

Box 24. Working together – or not:
What to do in cases of opposition and resistance

As the sexual health agenda is characterised by active opposition from religious groups and conservative governments and organisations, any NGO involved in the promotion of HIV/AIDS activities and sexual and reproductive health and rights can expect to be subject to a certain degree of resistance. The nature of the opposition will depend on the national context, but it is important to remember that not everybody agrees on, for example, the definition of the "family", the age that sex education should be introduced to pupils in school (if at all), women's role in society and the use of contraception. NGOs must know their values and how they wish to defend them. If, for example, the religious opposition in a project area is very strong, it is not realistic to encourage the church to support something it has traditionally not adhered to, e.g. the use condoms or referral to providers of legal abortion. It makes better sense to try to establish common ground on some basic values to avoid direct opposition or simply not involve the church at all in an effort to avoid antagonism.

NGOs sometimes have difficulty in collaborating with each other and are reluctant to share information due to organisational politics and the strong competition among like organisations for donor support. This must be overcome, and one successful example of this is EuroNGOs, a network of "European NGOs for Sexual and Reproductive Health and Rights, Population and Development", which works both in Europe and around the world. Their joint website (www.eurongos.org) shows how collaboration can be much more effective than "going it alone". For example, member organisations of EuroNGOs regularly apply for joint project funding by forming strategic partnerships among the relevant members.

Greater Involvement of People Living with HIV/AIDS – the GIPA principle

Once the right institutional setup has been established, the next step is to ensure the participation of the relevant stakeholders from the target group. In any HIV/AIDS-related activity, the quality of the response will depend on how well the project succeeds to draw on the insights of people affected and infected by the epidemic. Notwithstanding, PLWHA have for a long time not been involved in international, national and local decision-making regarding the design, implementation, resource allocation and evaluation of programmes that concern them. The reasons seem to be twofold. Firstly, decisions-makers within the donor community and the implementing agencies, including most NGOs, have been late to overcome their own prejudices and to recognise that PLWHA are not just victims but also have valuable experience and understanding to offer. Secondly, because PLWHA, often rightly, have been reluctant themselves to disclose their status and participate in NGO work, either out of fear of stigmatisation or because they simply had other, more time-consuming and urgent problems to cope with than organisational work.

However, at the 1994 Paris AIDS summit, the international community adopted the principle of greater involvement of people living with HIV/AIDS – (the GIPA principle) which was endorsed in 2001 by the UNGASS declaration (see the Chapter 4 on the rights-based approach). That means that no organisation that works on the basis of any UN declaration can ignore the participation rights of PLWHA. The Paris Declaration calls for: "… determination to mobilise all of society – the public and private sectors, community-based organisations and people living with HIV/AIDS – in a spirit of true partnership" and to involve "people living with HIV/AIDS in the formulation and implementation of public policies…". (Report on the global AIDS epidemic, UNAIDS, 2004:184). As shown in Figure 4 PLWHA can be meaningfully involved on a number of levels.

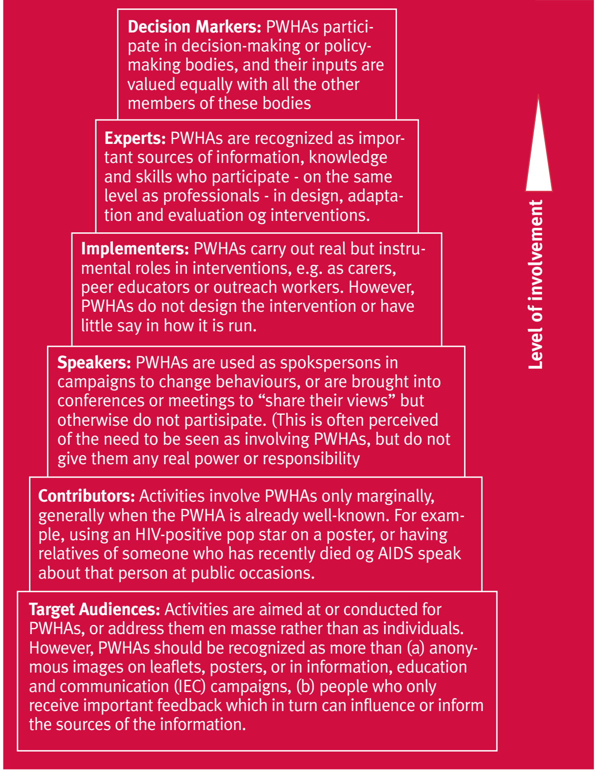
Why involve PLWHA at the highest levels of the project?

PLWHA should be involved because any organisation that operates with a rights-based approach must recognise the important role that those infected by HIV have in improving their own situation. In addition, the participation of PLWHA can strengthen project activities. By involving PLWHA from the beginning, they become co-owners of the programme and have more of an incentive to participate. They have, after all, become experts on living with the virus and understanding its impact on a personal or community level. They hold valuable information, and it seems obvious that it is better to talk with PLWHA than about them. NGOs can learn a great deal about how to fine-tune their HIV/AIDS interventions from the target group itself. Finally, the active involvement of PLWHA can contribute to the reduction of stigma and denial by providing an alternative to the picture of HIV-positive individuals as "patients" or "victims" from so-called high-risk groups. The involvement of PLWHA as staff, volunteers, peer educators or advocates, based on their individual skills and competencies, empowers them to improve their own situation, change their attitudes and beliefs and, ultimately, contributes to the normalisation of HIV/AIDS.

A pyramid of involvement by PLWHAs

It must be recognised that even among groups that are considered to be vulnerable, there will always be a hierarchy of power and

Figure 4. The GIPA principle



Decision Markers: PWHAs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies

Experts: PWHAs are recognized as important sources of information, knowledge and skills who participate - on the same level as professionals - in design, adaptation and evaluation og interventions.

Implementers: PWHAs carry out real but instrumental roles in interventions, e.g. as carers, peer educators or outreach workers. However, PWHAs do not design the intervention or have little say in how it is run.

Speakers: PWHAs are used as spokspersons in campaigns to change behaviours, or are brought into conferences or meetings to "share their views" but otherwise do not partisipate. (This is often perceived of the need to be seen as involving PWHAs, but do not give them any real power or responsibility

Contributors: Activities involve PWHAs only marginally, generally when the PWHA is already well-known. For example, using an HIV-positive pop star on a poster, or having relatives of someone who has recently died og AIDS speak about that person at public occasions.

Target Audiences: Activities are aimed at or conducted for PWHAs, or address them en masse rather than as individuals. However, PWHAs should be recognized as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive important feedback which in turn can influence or inform the sources of the information.

Note: This pyramid models the increasing levels of involvement advocated by GIPA, with the highest level representing complete application of the GIPA principle. Ideally, GIPA is applied at all levels of organisation.
Source: UNAIDS (2004) From Principle to Practice.

Resources

- **ILO (2001). Implementing the ILO Code of Practice on HIV/AIDS and the world of work (www.sacob.co.za)**

This training manual is a tool to complement the ILO Code, widen its reach and strengthen its applicability. It emphasises practical activities and guidelines to help users apply the Code to national strategic plans and to develop targeted and effective workplace policies and programmes. It is also a source of information on HIV/AIDS from the perspective of the world of work.

- **Horizons Program (2001). Interventions to Reduce HIV/AIDS Stigma: What Have we Learned? (www.popcouncil.org/pdfs/horizons/litrvwstigdisc.pdf)**

This paper reviews 21 interventions that have explicitly attempted to decrease AIDS stigma both in developed and developing countries and nine studies that aim to decrease stigma related with other diseases. The studies reviewed here show that we can do something about stigma and that it can be reduced through a variety of intervention strategies.

- **International Council of AIDS Services Organizations (ICASO) 1997. HIV/AIDS Networking Guide: A compre-**

influence. This is also the case among PLWHA. They are not equally vulnerable and some have a stronger voice and better support than others.

Gender differences and the divide between the rich and poor play a role that is often ignored in the all-encompassing abbreviation PLWHA, where the ‘P’ tends to mask any differentiation among the group’s members. It is not the same to be an HIV-positive man, breadwinner of the family with support from your workplace, wife and family as to be a single, young woman or an HIV-positive child born out of wedlock.

Women, young people and children are often underrepresented as decision-makers, experts and advocates in the existing networks of PLWHA. Not only do they not have access to the benefits that are related to these networks (e.g. jobs, medical care and invitations to conferences); their insights and viewpoints are also not given due consideration.

Creating a space for PLWHA in your organisation/partnership

Participation is a right, not an obligation. However, if people are reluctant to demand their rights, NGOs have a moral obligation to empower them to exercise these rights and demand their entitlements. NGOs can create an environment that makes it safe and attractive for PLWHA to become involved. This has the added benefit of establishing a project framework that could also be inclusive of other hard-to-reach populations.

In short, this is an empowerment issue; it is about changing the way people think about themselves and promoting positive changes in attitudes and behaviours. The target group should therefore not only be PLWHA, but also people in close contact with them. The indicators of success could include that PLWHA take the initiative to make changes in their own lives and that they organise activities to support their needs and those of other PLWHA.

■■■ Entry points for NGOs

■■Create workplace policies and action plans that define the rights and responsibilities of employers and staff members in relation to HIV/AIDS. These policies should include specifications on medical coverage of chronic diseases, flexible working hours that allow people to attend medical check-ups, protective measures on positive living, psychosocial support, rules about confidentiality and a non-discrimination message;

hensive resource for individuals and organisations who wish to build, strengthen or sustain network (www.icaso.org/docs/icasonetwknguideng.pdf)

This guide is a tool to enable individuals and organisations to improve their ability to build and sustain a successful networking approach. NGOs are encouraged to adapt it to their specific needs by adding sections relevant to their development.

- **The Global Network of People Living with HIV/AIDS(2005) Challenging, Changing, and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanism (www.gnpplus.net/files/%20CCM_Handbook-EnglishV1.pdf)**

This handbook is the product of numerous consultations and input of over 400 people living with HIV/AIDS (PLHIV) from more than 30 countries in every region of the world. It was created primarily for PLHIV who are already working on HIV/AIDS issues in their countries and who are interested in increasing their involvement and influence in the Global Fund to Fight AIDS, Tuberculosis and Malaria.

- Develop staff capacity to address HIV/AIDS and to involve PLWHA through ongoing training of staff members in NGOs in donor and recipient countries;

- Ensure that NGO staff have the right cultural and gender-based sensitivity to work with the communities;

- When involving PLWHA and other vulnerable target groups, be aware of their financial needs and ensure that they receive an appropriate salary or compensation for their work and time;

- Look out for self-help groups, post-test clubs and others that could be transformed into more project-oriented activities through capacity building and support;

- Ensure that PLHWA that are involved as project implementers, peer educators, advocates and the like receive the necessary training, monitoring and support to actually be able to carry out the tasks to which they are assigned;

- Apply pressure on insurance companies, sub-contractors and other business partners to ensure that they do not discriminate against PLWHA. □

25. Advocacy

Advocacy is a particular way of communicating and is often confused with the concept of information, education and

Table 4. Advocacy and related key concepts

	Advocacy	Information, education and communication	Community mobilisation	Networking and partnerships	Fundraising and resource mobilisation	Overcoming stigma and discrimination
What can it change?	Policies, implementation of policies, laws and practices	Awareness and behaviour	Capacity of communities to identify and address their problems	Isolation and duplication	Level of resources available for HIV/AIDS work	Level of stigma and discrimination against PLWHA
Target group	Decision-makers, leaders, policy-maker, people in positions of influence	People of a particular gender or age group, residents of a particular area, etc.	Members of a particular community	Individuals or groups with similar agendas	Communities, local councils, government, donors	People who stigmatise or discriminate
Typical indicators of success	Policies, implementation, laws or practices which enable improved HIV/AIDS prevention and care, budget allocation, formation of alliances	Percentage of youth using condoms; changes in attitude to people living with HIV/AIDS, increased awareness, changes in attitudes, skills and behaviour	A community problem is solved; more people attend community meetings	Members of the network or partnership achieve more than they could if they worked alone	Local officials allow a building to be used for meetings; members of mosque give alms; donor gives grant	Fewer workers dismissed due to HIV status; fewer cases of depression among PLWHA

Source: Adapted from: International HIV/AIDS Alliance (2002). “Advocacy in Action – A toolkit to support NGOs responding to HIV/AIDS”.

communication (IEC), which is more concerned with behaviour change interventions. However, advocacy is more than dissemination of information as it aims at influencing and changing policy, laws or programmes in a certain direction. The table below provides an overview of how the various concepts can be differentiated.

Advocacy can take place at many levels and among many different stakeholders. For example, some countries still do not have well-developed HIV/AIDS policies and national action plans in place; organisations including donors and NGOs might work hard to influence governments to change this. Another example could be a country with a national action plan already in place but with inadequate focus on certain aspects, such as men who have sex with men (MSM) or STI prevention. In order to change such situations, individual NGOs, NGO networks or interest groups may choose to initiate an advocacy campaign directed at the government

As noted in previous chapters, the approach for dealing with the HIV/AIDS epidemic has been medicalised because in many countries the health sector has shouldered the main responsibility in responding to the epidemic. However, advocacy is a strong tool in trying to broaden the response to the epidemic to other line ministries outside the health ministry, such as the ministry of education or ministry of internal affairs, as each of these ministries has important contributions to make in the fight against the epidemic. Additionally, employers' organisations and trade unions in several countries have decided to engage in the fight against the epidemic due to, among other things, strong advocacy efforts.

One advocacy strategy is to mobilise "Goodwill Ambassadors" or "Ambassadors for Change" from among celebrities with a positive public image such as political or religious leaders or famous pop or sports stars. The ambassadors promote specific advocacy messages in order to help bring about a change of attitude in the general public. One example is Mechai Viravaidya, a Thai senator, who actively promoted the 100% condom use campaign in Thailand in 1991 and 1992. In 1999 he became a UNAIDS Ambassador and condoms in Thailand are still sometimes referred to as Mechais.

In many countries, it has proven crucial to "give AIDS a face". The American film star Rock Hudson had a great influence in the USA when he went public with his having the disease, and the Ugandan pop musician Philly Lutaya had a huge influence in Uganda by speaking freely of AIDS during the last years of his life. That was also the case with the Nigerian Afro-beat singer Fela Kuti who died from AIDS-related causes in 1997 at the age of 58.

Box 25. Benefits of networks

- Keep you up to date on what other organisations are doing in a specific field;
- Provide a strong platform of allies for advocacy;
- Provide access to varied and multiple resources/skills;
- Pool limited resources for the common goal;
- Achieve things that single organisations or individuals cannot – power in numbers;
- Help to refine your argumentation through internal debate among peers;
- Form the nucleus for action and attract other networks;
- Expand the base of support.

Source: The Policy Project (1999). "Networking for Policy Change – An Advocacy Training Manual".

Resources

- **International Council of AIDS Service Organizations (ICASO). Advocacy Guide to the Declaration of Commitment on HIV/AIDS (United Nations General Assembly Special Session on HIV/AIDS June 2001) (www.icaso.org/ungass/advocacyeng.pdf)**

This short but useful document contains recommended strategies for NGOs to pursue in order to ensure that the Declaration of Commitment on HIV/AIDS is respected in the

Networks

As described in Chapter 28, NGOs have the comparative advantage of often being able to facilitate the self-defined expression of marginalised groups such as PLWHA or children. However, in order to ensure that advocacy efforts have as great an impact as possible, it is crucial that NGOs speak with a common voice and share a vision of what they want to change. At a minimum, it is important that they do not contradict each other in their advocacy messages, which unfortunately is often seen. Establishing NGO networks can be an excellent way of achieving this, provided that there is an open and honest dialogue among the members of the network. The advantages of networks are listed in Box 25.

How should people working in the field of HIV/AIDS and/or SRHR decide what issues to advocate for when there are so many competing needs and priorities? Is it better to advocate for safe motherhood issues rather then prevention of mother-to-child transmission of HIV or harm reduction? Naturally, it is not a question of one or the other; but it is imperative to define priorities, especially in low-income countries with insufficient funds to combat the epidemic efficiently or improve the sexual and reproductive health situation.

However, one overarching theme, which all stakeholders can or at least should agree is a pivotal advocacy theme is the protection of the human rights of individuals. As IPPF has stated: “An effective response requires the implementation of all human rights, civil and political, economic, social and cultural. Public health interests do not conflict with human rights. On the contrary, it has been recognised that when human rights are protected, fewer people become infected and those living with HIV/AIDS and their families can better cope with HIV/AIDS”.

How do you advocate?

In order to ensure that advocacy message have the intended effect and impact, it is important to undertake a certain analytical process. In the following, the main steps of the advocacy process will be presented in short.

I. Define the issue. Advocacy begins with an issue or problem that is agreed upon in order to promote a change of policy. In order to define the issue, an analysis of the external environment, including political, economic, social and other factors is important. Additionally, collecting and analyzing data about the HIV/AIDS and SRHR situation is important.

II. Set goal and objectives. The advocacy objective describes short-term, specific, measurable achievements that contribute to the fulfilment of the advocacy goal.

countries where they work. In addition to widely disseminating the Declaration, it is encouraged that priorities be set and that governments be held accountable to the Declaration.

- **International HIV/AIDS Alliance (2002). "Advocacy in Action – A toolkit to support NGOs and CBOs responding to HIV/AIDS (www.aidsmap.com)**

This toolkit aims to help NGOs/CBOs gain a clear understanding of what advocacy is and how it might support the work of NGOs and CBOs, and to provide practical assistance on how to actually undertake advocacy work. It addresses the advantages of planning advocacy work systematically and how this can be achieved. It also helps organisations consider how advocacy could help them achieve their mission and to recognise the potential impact of advocacy work on their organisation.

III. Identify the target audience. The primary target audience usually includes decision-makers with the authority to bring about the desired policy change. The secondary target audience includes individuals who have access to and are able to influence the primary audience: other policy-makers, friends or relatives, the media, religious leaders, etc.

IV. Build support. Building a constituency to support the advocacy issue is critical for success. The larger the support base, the greater the chances of success.

V. Develop the message. Advocacy messages are developed and tailored to specific target audiences in order to frame the issue and persuade the receiver to support the position. There are three important questions to answer when preparing advocacy messages: Whom are you trying to reach with the message? What do you want to achieve with the message? What do you want the recipient of the message to do as a result of the message?

VI. Select channels of communication. The most appropriate medium for advocacy messages depends on the target audience. The requirements differ for the variable tasks of reaching the general public, influencing decision-makers, educating the media, generating support for the issue among like-minded organisations/networks and so on. Some of the most common channels of communication for advocacy initiatives include press kits and press releases, press conferences, fact sheets, a public debate, and conferences for policymakers.

VII. Raise funds. A fundraising strategy should be developed at the outset of the campaign to identify potential contributors of financial and other resources.

VIII. Develop implementation plan. An implementation plan to guide the advocacy campaign is important. The plan should identify activities and tasks, the persons/committees in charge, the desired timeframe and needed resources.

Often, it is not possible to follow each step in the advocacy process according to the model presented here. Nevertheless, a systematic understanding of the advocacy process will help advocates plan wisely, use resources efficiently and remain focused on the advocacy objective.

Resources

- **IPPF HIV/AIDS Advocacy Guide (www.ippfwhr.org/publications/publication_detail_e.asp?PubID=60)**

This guide, which is intended to supplement IPPF’s Advocacy Guide, describes what advocacy can do, often at little cost, in the prevention of HIV/AIDS. It offers insight into working with target populations and profiles successful IPPF Member Association programmes throughout the world.

■■■ Entry points for NGOs

■■ Strengthen the voice of e.g. PLWHA in the fight against the HIV/AIDS pandemic by facilitating the establishment of networks;

■■ Organise advocacy capacity-building workshops which identify key messages and target audiences;

■■ Ensure that there is a strong NGO network which is able to speak with one voice on the subjects of HIV/AIDS and related issues. □

26. Capacity development and training

Many readers of this manual will have experienced training sessions related to HIV/AIDS and SRHR work. They will probably have been of varying effectiveness, some with failures related to follow-up, and perhaps even the dilemma of high per diems or “meeting fees” for many participants and organisers. Training is often important and necessary, but is not the sole solution for controlling HIV or improving SRHR. Although training is given to the individual, its aim is to strengthen the organisation. Most training is on-the-job training, with the purpose of improving the quality of work, i.e. the results.

Clearly the current response does not match the scale of the HIV/AIDS epidemic and the magnitude of the reproductive health related problems. For some years, strategies to scale-up the response have seen increasing emphasis. However, scaling-up not only requires identified, cost-efficient “good practices” that would be beneficial to take to scale, but also ample funds and not least qualified human resources to implement the projects/programmes. That is the focus of this chapter.

Developing the capacity of individuals and organisations and sometimes reorienting them towards dealing with a new situation requires a lot of time, effort, money and commitment from the organisation. Furthermore, experience has shown that transfer of technical skills related to health is far easier and more convenient than developing competencies in dealing with crucial rights aspects that form the underlying causes of poor health. Whereas the call for training health-specific and managerial competencies is in general acknowledged, the need for training for rights-based approaches and ethics can be more contested and often neglected. This kind of training can be on clients’ rights, women’s and young people’s rights, and build on values concerned with bodily integrity, equality and integrity. To provide training on rights includes basic information about the ethical content of sexual and reproductive rights and the rights of PLWHA but also includes training personal attitudes of health-care providers, educators and other NGO staff. This is obviously a more demanding and challenging process, which NGOs must nevertheless be ready to embark on.

Experience from many programmes aiming at introducing behaviour change shows that some important prerequisites need to be fulfilled for training activities to have the maximum desired effect. Not meeting these prerequisites may lead to no effect at all – or even a sense of pessimism in the organisation.

1. Training objectives, content and form – who decides?

The objectives of the training activity must be clear to the organisers as well as to the participants. When defining what is to be shared with the participants, the organisers establish what the participants need and what they already know by checking their priorities and knowledge in advance. Furthermore, it is useful to establish so-called “learning contracts” with the participants and to reiterate the contract throughout the training sessions. This approach is especially effective when “pre-tests” are carried out together with a few representatives of the target group, and these representatives also contribute to the planning of the first sessions and the later follow-up. Such “participatory approaches” tend to be highly useful.

2. Overall strategy – where does training fit in?

Training activities, important as they are, should only be implemented in the context of a strategic plan. Is it a long-term or short-term project, big or small, and what are the expected outcomes and potential partners? Apart from essential supportive supervision, are other interventions needed, such as condom distribution or the development of additional written materials.

Box 26. Preparing the ground for antiretroviral drugs

Before beginning the distribution of antiretroviral drugs, it is necessary to prepare a communication strategy for the community, groups of PLWHA, patients, the public health-care sector and other NGOs. This could be done via radio or community meeting. At the same time, health-care staff need to be trained according to previously agreed guidelines, and when they return to work after training, the drugs, test kits and other equipment need to be in place, and the staff need a planned follow-up visit by a supportive supervisor no later than 2-3 weeks after the training. If this process is not planned and coordinated well in advance, the results are likely to fall far short of expectations

3. Time perspective

Any training session – an hour, a few days or weeks – will have much less chance of yielding results if it stands alone than if it is one in a series of several, or, even better, a regular component of a systematic training activity. HIV-related activities should be mainstreamed into in-service training programmes. Teachers, nurses or water engineers meet regularly to discuss issues of common interest and obtain new knowledge, and it would be useful if part of some of these sessions could deal with the challenges of HIV/AIDS encountered in their respective work.

4. Enhancing effects of training activities

The potential of training situations can be improved by preparing the individual participant during the training for expected barriers to change. This can be done with role playing games based on the transfer of practices and strategies, the establishment of networks to continue the development of issues in focus during the training or the involvement of “training facilitators” into change processes or “supervisors” into training activities.

5. Follow-up

Some successful programmes have found that there is no point in providing any training at all if there is no pre-planned follow-up. This means that already before carrying out any training, the next sequence of steps must be planned, such as additional training activities and, importantly, supportive supervision. “Supervision” can mean painful inspection by a higher-ranking individual; but it should be “constructive supervision” by a knowledgeable and committed person who shows up soon after the initial training, and then regularly, assists in implementing the lessons learned – whether the task is to provide outreach care for orphans or to provide VCCT for HIV.

6. Participation

What has been learned very clearly from the HIV/AIDS pandemic is the need to act together with the most involved groups themselves and the NGOs that work with them and have their interests at heart. Globally, sexual transmission of HIV is by far the most common form of transmission and a top-down or mass media campaign in isolation will not significantly change people’s sexual practices. People must be involved and committed, have influence and voice, and be able to participate and take part in any change process, including the ones involving training. As this manual reflects, the HIV/AIDS pandemic raises numerous additional issues – such as vulnerable groups, discrimination, co-infections, violence and home-based care – that in their totality are far beyond what most governments and public bodies (e.g. ministries or schools) can deal with. This is true both from a capacity perspective – the amount of work that needs to be done – and with regard to skills. The skills of experienced community workers, PLWHA and NGO activists are sorely needed to bring this pandemic under control.

7. Evaluation

The efforts of capacity strengthening, including through training, should be evaluated. This means not only as regards pure knowledge, but also to what extent the organisation has improved. For example, have the staff changed their behaviour, focus, understanding and learning methods?

8. Contributing activities

Other simultaneous organisational activities will heighten the impact of the capacity strengthening activities mentioned above, such as the introduction of self-governing for small groups, quality improvement circles, changed incentive systems and changes in recruitment.

Entry points for NGOs

- In any kind of training on HIV/AIDS, it can be useful to invite an HIV-positive person to contribute and share his or her experience, especially in environments where few people are open about their status. NGOs need to link up with networks of PLWHA in order to identify a person living with HIV who is able to participate;

- In HIV/AIDS training, linkages should be drawn to SRHR by having participants identify the connections of HIV/AIDS to SRHR and possibly to gender and poverty;

- Ensure that training not only focuses on technical, health-related aspects but also on rights and ethics;

- Ensure that training activities within your organisation, or that you participate in, are part of a larger strategic plan including other supportive activities;

- As NGOs, be prepared to define the need for and to initiate relevant training/capacity-building activities, and take part in their planning and implementation. □

27. Monitoring and evaluation

Both monitoring and evaluation are necessary components of any intervention. Monitoring must be continuous, with some parameters checked every week or month in order to be sure that the project is moving in the right direction. It will be difficult to continue the project/programme after 1-2 cycles if there are no results reflected in an evaluation (funding is too limited to allow for long-term support for activities whose effect is not proven). The comparative benefits of a certain project/programme therefore need to be shown and documented. With AIDS consuming an increasing amount of the resources in many countries, which are simultaneously often becoming poorer due to AIDS, budget allocations for the most effective interventions need to be ensured. If the results of a project are all negative, a new phase can only be proposed if those negative results are stated, and changes proposed.

Box 27. Key definitions

Monitoring means overseeing or making sure that a project is going in the right direction as it progresses, by using pre-selected indicators.

Evaluation means assessing the overall achievement of a project or programme at the end or at pre-defined intervals (annually or every three years, for example). Evaluation is often used synonymously with review; in Danida terms an evaluation is carried out only after the project has ended.

Output indicates what the project has produced in practical terms (e.g. number of nurses trained, safe units of blood delivered, number of condoms sold and number of persons counselled and tested).

Outcome indicates the changes brought about by a project, such as better knowledge, changed attitudes, changed behaviour and condom use.

Impact indicates the effect or the ultimate desired change brought about by the project, such as reduced HIV incidence, surviving PLWHA or improved quality of life, usually related to the objective of the project.

A "project" usually means a time-limited set of activities or "interventions" with a specific objective, while a "programme" usually means a larger, more comprehensive undertaking comprising multiple projects or components with several objectives. Sometimes the word "programme" is used about a project that has developed over time to become a set of regular and continuous ongoing core activities. Both need monitoring and evaluation.

Often, both projects and programmes that are run by public authorities are run by one public sector (such as health, education or forestry). NGOs have a special potential role in implementing inter-sectoral projects with a set of interlinked interventions, e.g. in schools and for workers and in health care in a district. This is discussed in the section on district planning. When a programme is inter-sectoral, both the monitoring and the evaluation presents special challenges as information must be gathered from these different sectors, assessed jointly and fairly, and be used for re-assessment and re-thinking of the next phase.

Monitoring therefore requires a set of predefined indicators showing the progress of a project or programme, both as a whole and as certain landmark achievements, "milestones". These indicators often concern activity outputs, such as training sessions held, number of people trained, buildings erected, agreements made and condoms distributed. They should be easy to register and document, and the routine nature of this set of indicators often means that they are output-related rather than impact-related. Ideally, they should be closely linked to the detailed schedule of the project/programme, and the "chronogram" of the planned cycle (2-3 years) can be monitored through these indicators. Milestones are usually indicators monitored at certain predetermined points in time; as the name suggests, they constitute intermediary goals such as the completion of an initial phase of a project or having reached a phase of full implementation of a certain programme. Monitoring to a large extent concerns the assessment of process indicators (see figures).

Evaluation, on the other hand, means assessing the achievements (which could be outcome or impact) of the project/programme, and this requires a more thorough analysis of what was achieved at the "recipient level", that is the level of the intended beneficiaries of the activities. Evaluation requires more work and therefore cannot be done either continuously or annually, but rather in the time perspective of a typical project or programme, 2-3 years. One year is usually too little and five years too much for modifying an inefficient project/programme. To be able to measure the outcome or impact of a set of activities at the beneficiary level, we need to have a starting point to compare with. This is the baseline study, or initial assessment, carried out before initiating activities or, in the case of a continued project/programme, at the start of a new cycle. See Figure 3 in Chapter 22. To be able to compare the results after 2-3 years of work with the initial situation, the indicators need to have been agreed upon at the beginning: knowledge, attitude and practices (KAP) on safer sex, as found in a certain questionnaire; number of orphans supported through school; district plans including projections of extra human resources needed due to AIDS losses and so on. To a large extent, evaluations address the assessment of outcome or impact indicators.

A special problem when working with HIV/AIDS is the fact that as the pandemic evolves in a country, indicators will worsen. Many very good projects/programmes will therefore see a worsening of certain health related indicators. The situation would perhaps or probably have been even worse if the project had not been there. For this reason it is important to not only include health evaluation indicators related to the epidemic, but impacts such as behaviours, care, policies and legislation – phenomena at the beneficiary level that are not all directly dependent on the spread of HIV/AIDS.

A special feature of evaluation is economic evaluation. Many stakeholders – neighbouring district authorities, other sectors, NGOs and donors – may wish to know the cost of a certain project/programme, and what was achieved. In every programme, efforts should be made to keep track of costs in order to respond to such queries, although external justification should not dominate the project/programme.

Some projects/programmes will be preceded by a testing stage, in which there will be a comparison site where the particular interventions are not carried out, or carried out in another fashion. This is what is known as a trial, comparing two different sites and/or two different sets of interventions. The practical, ethical and scientific challenges of doing this are dealt with in specialised literature. This manual underlines the practicalities of carrying out a set of activities shown to be effective elsewhere (in trials) in the best ways possible.

Surveillance is a common expression in HIV/AIDS work and means following what is developing as regards the actual prevalence and spread of HIV and of sexually transmitted infections.

Four good rules for monitoring and evaluation:

1. Decide on the indicators when planning the project or programme cycle – not at the end of it! When planning a new project or the continuation of a project/programme in the team spend the needed time discussing and agreeing on these

Resources

- **Webb D and Elliot L (2002). Learning to Live: Monitoring and evaluating HIV/AIDS programmes for young people (www.savethechildren.org.uk/temp/scuk/cache/cmsattach/211_learning2livecond.pdf)**

This handbook was developed for Save the Children and as such focuses on programmes for young people, e.g. school-based education and peer education. The main goal is to introduce the concepts underlying project monitoring and evaluation and to demonstrate how these are practically applied in HIV/AIDS projects. Examples of methods and procedures which can be used in monitoring and evaluating HIV/AIDS projects are given and there is an important section on the role of indicators.

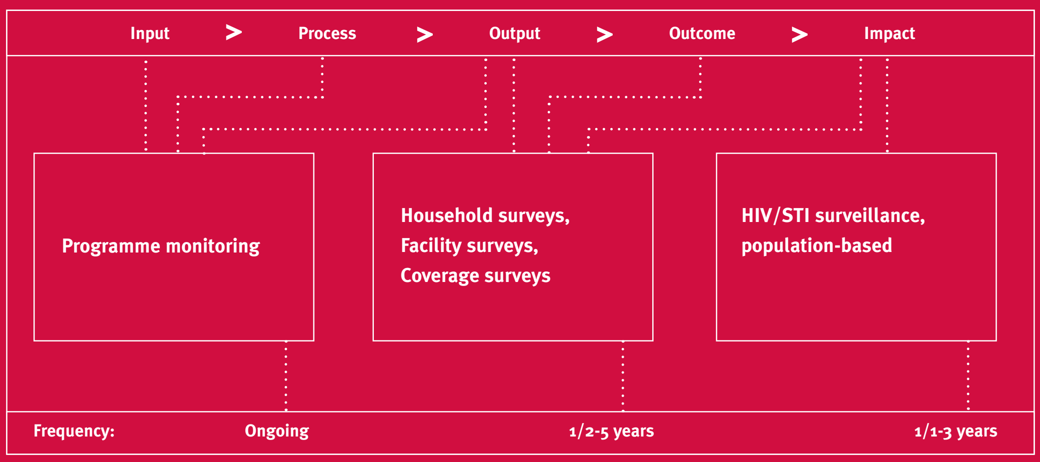
- **Guidelines for developing a workplace policy and programme on HIV/AIDS and STDs (www.ahi.co.za/aids/intro.html)**

This South African online resource outlines the basic elements of HIV/AIDS and STD policies and programmes that can be implemented in workplaces. Much attention is devoted to monitoring and evaluation, and this section suggests relevant indicators for workplaces such as the prevalence of HIV infection among employees, numbers of condoms distributed and the number of employees attending HIV/STD education programmes.

- **Øvretveit J. Action Evaluation of Health Programmes and Changes. A handbook for a user-focused approach (www.radcliffe-oxford.com)**

This book is a practical introduction to evaluation. It not only deals with the nuts-and-bolts of how to evaluate but also discusses why evaluations should be undertaken and the ethics of evaluating. The many examples increase its usefulness for the reader.

Figure 5. Data collection and frequency for monitoring and evaluation



- **Family Health International (2001). Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries: A Handbook for Program Managers and Decision Makers (www.fhi.org/en/HIVAIDS/pub/index.htm)**

This is a 17-chapter handbook that helps develop strategies for programme evaluation in low-income countries. It addresses the role of evaluation in HIV/AIDS programmes, approaches for evaluating intervention strategies, methods for measuring behavioural trends and ways to assess programme impact.

- **WHO/UNAIDS (2004). National AIDS Programmes: A guide to monitoring and evaluating HIV/AIDS care and support. WHO, Geneva (www.who.int/hiv/pub/epidemiology/pubnapcs/en/)**

This guide, developed by six organisations, aims to support national AIDS programme managers in monitoring and evaluating public and private care and support programmes for HIV/AIDS. As more governments move towards increasing access to prophylactic and long-term treatment and care, such a guide will contribute to a global process of assessing whether care and treatment programmes are developed and implemented well.

- **UNFPA. The Programme Manager's Planning, Monitoring and Evaluation Toolkit. (www.unfpa.org/monitoring/toolkit.htm)**

This toolkit supplements the UNFPA programming guidelines. It provides guidance and options on how to improve planning, monitoring and evaluation activities in the context of results-based programme management. It also includes an extensive glossary of important terms related to the material in this chapter.

indicators. Write them down, and prepare in as much detail as possible to continuously monitor these indicators and to collect them at certain points in time for evaluation. How will they be collected? By whom? The logical framework ("log frame") planning model includes defining such details, but any basic planning should include this.

2. Select simple indicators! They should be intuitively simple to understand, reflect what you want to achieve, robust (not too sensitive to unimportant shifts), and as easy as possible to collect.

It is better to choose something simple that you can do without great effort than something that looks nice on paper but that you cannot do in reality.

3. Involve the project/programme participants in the monitoring and evaluation as far as possible. Journalists or schoolteachers surely will both have views on the type of data to collect, on how to collect it, and possibly also an interest in actually collecting (at least if it is not a significant extra burden). This will increase their ownership in the project and help influence it positively.

4. Adapt national and indicators HIV/AIDS indicators to the project to the extent possible. ☐

Resources

- **The NGO HIV/AIDS Code of Practice Project (2004). Renewing our voice: Code of Good Practice for NGOs Responding to HIV/AIDS (http://www.ifrc.org/what/health/hivaids/code/index.asp)**

This code describes in a unique way a set of principles for good practice of NGOs that are involved in the fight against HIV/AIDS, in other words how we do our work best. It is an important document because it represents a shared vision that has been initiated by a variety of Southern and Northern NGOs, of faith based organisations and of networks and then signed by a high number of international organisations.

28. What can NGOs do?

Twenty-five years into the HIV/AIDS pandemic, much has fortunately been learned. We now know that the dominant mode of transmission is through sexual contact, and we know how to prevent that and other types of transmission, some of which are becoming increasingly frequent, such as those of shared infected needles and syringes among drug users. We have also learned that while governments and international bodies have a key role in organising and financing activities that can prevent and mitigate HIV/AIDS, they often have quite limited capacity in implementing many of the most effective activities. This is because they are good at organising coordinated responses – when they set their mind to it – but are not well equipped to talk to people about sexuality or influence how we have sex.

When we first understood that an epidemic was underway, in the early and mid-1980s, there was a tendency to neglect the epidemic in some countries, because many saw it as a problem mainly affecting homosexuals, drug users and prostitutes. The title of the book *And the Band Played On* (1987), alluding to the orchestra that allegedly went on playing on the Titanic while the ship was sinking, reflects this short-sighted and, ultimately, reckless attitude. We had not yet understood how the pandemic would soon infect or affect all of us, everywhere. In those years, in some countries, those first affected, notably the homosexual community, were literally forced to take their own initiatives to respond to the epidemic. Few others cared. This epoch led to forceful action from homosexual groups, with explicit language used in group training to achieve "safer sex" (as entirely safe sex is not possible). This was actually the first forceful response to the epidemic: the groups most affected initiated, designed and implemented their own response, to protect themselves. This was, for example, the origin of what came to be a very effective national AIDS programme in Brazil (www.aids.gov.br), which has many lessons to teach us today.

In some other countries, the ministry of health was in charge of much of the AIDS-control activities. Working mainly in isolation, they often failed. HIV/AIDS is a health problem, but it is also much more, and we have learned from bitter experience that ministries of health cannot be given the sole responsibility for fighting the epidemic. All ministries and all public and non-governmental authorities must collaborate to initiate, design and implement the actions needed.

This clearly tells us that non-governmental organisations must assume a major role in inspiring, initiating and promoting HIV/AIDS activities. A particularly important role in this work is to ensure the representation of high-risk groups or those otherwise implicated. Homosexual groups, networks of commercial sex workers and PLWHA must be involved in the planning and design of many of the activities. They are the experts on their own practices and their relation with the disease. Where possible, intravenous drug users should also be involved. However, drug abusers are often unreliable partners due to their addiction. Working with people with a previous history of drug abuse is a better option. While this may seem obvious to many readers, it is particularly tragic that some countries today not only criminalise

The publication and synthesis poster covers a set of Guiding Principles, of Organisational Principles and of Programming Principles all founded in a rights based approach and in best available evidence. It is short and easy to use and provides a wealth of useful and well categorised references.

NGOs willing to sign the Code can use its principles as an advocacy tool as well as a support for developing their own HIV/AIDS strategies.

drug users, commercial sex workers and sometimes homosexuals but even try to jail such individuals. Instead of helping to control the epidemic, the threat of incarceration has the opposite effect, often driving the activity underground and furthering the spread of HIV/AIDS, while prisons themselves are major settings for the spread of HIV.

Both the ideas and the energy for effective HIV/AIDS work often tend to come from non-governmental organisations. Such organisations can be more flexible, innovative and pragmatic than public bodies. NGOs can try out new interventions on a small scale in a country - often even activities that are not generally approved of by the authorities, such as condom distribution or needle and syringe exchange. National NGOs can, with their local expertise combined with the technical and financial support of international NGOs, sometimes break the ice in a country with a new type of intervention. At best, this can help persuade the government to introduce the intervention nationwide after due adaptation to the country setting.

In addition, NGOs can give a voice to the voiceless: the poor, the homeless, the handicapped, street children, commercial sex workers, people living with HIV/AIDS and, in some countries (where illegal), homosexuals – a voice that is magnified and modulated to both express their needs and reflect their expertise and involvement.

Combating HIV/AIDS is also about empowering women - empowering them to say no to sex and to use condoms when they want to. Here, it is clear that NGOs have a particular role to play in supporting the transition to a less gender-discriminating society.

Human rights are another reason for NGOs to mobilise in the fight against HIV/AIDS. Most countries favour human rights in principle, but in reality, due to financial, cultural, religious or other factors, they are not always enforced. “Watchdogs” are needed to point out critical issues concerning human rights abuses – issues that should be taken into serious account because they also reflect evidence-based approaches to reducing the spread of HIV. Religious organisations potentially have a huge role to play in the defence of human rights.

Entry points for NGOs

- NGO or networks of NGOs should be sure to express their views and experiences via multiple channels, e.g. the mass media, government offices, schools and direct contact with the population at large. Messages should reflect core values and suggest innovative approaches tried in the country or elsewhere;

- Assess the HIV/AIDS policies of your NGO and consider in which area you could strengthen current HIV/AIDS-related activities or initiate new ones;

- Form networks committed to working on HIV/AIDS issues or join existing networks, as collaboration usually increases effectiveness;

- Ensure NGO network representation on the National AIDS Commission or similar high-level entities.

Appendix: How did we choose the material for this manual?

A. What is the "evidence base" in medicine?

The expression "evidence-based medicine" was first used in 1990, and is now commonly accepted with regard to all health-care interventions. We have learned to ask if the particular intervention has been scientifically proven to provide more good than harmful effects. And we investigate both the degree of these effects and the quality of the evidence that the results of scientific studies are based on. The reason for this growing interest in evidence is simple: it is unethical to spend scarce funds on interventions with little or no proven effect. While this is true for all health-related actions, it is even more important with regards to the HIV/AIDS pandemic, an incurable disease that primarily infects poor people. NGOs working in the field of HIV/AIDS prevention, mitigation and treatment must therefore be able to answer the question: Is what we are doing useful?

The cornerstone of "evidence-based medicine" is the randomised controlled trial (RCT). The best evidence in studies of the effectiveness of health interventions comes from the RCT. In the RCT, the intervention in question, for example "does a particular medicine work", is applied to half of a certain group of individuals, selected at random (by lottery). The control group gets either no treatment or the current standard of treatment. One then calculates the difference in effect between the intervention and control groups, thereby assessing the effectiveness of the intervention. This appears like a simple and natural procedure, but it has revolutionised modern health care. Many classical treatments have been changed in recent years due to RCTs, and the RCT has changed our way of thinking.

We have also learned to merge the results of separate intervention trials – often performed in different parts of the world by different researchers and reported in different journals – to determine if all the results, or rather the merged results of many studies, point in the same direction. This is called a "meta-analysis" or "systematic review". In clinical health-care interventions today, "evidence" is commonly graded in the following way:

- Systematic review of RCTs
- One RCT
- Systematic review of cohort studies
- Individual cohort study
- Cross-sectional studies
- Ecological studies (these are detailed case studies, often as "before and after" an intervention
- Systematic review of case-control studies
- Individual case-control studies
- Expert panel report (is best used for supportive recommendations, as it is not hard evidence).

The above list illustrates that in clinical medicine, the way to work today is clear: expert opinion is considered to be of limited value. The grading reflects the quality of the evidence, meaning the probability that a scientific study will give the same result if it is repeated. The risk of getting different results increase through the list because the quality of the research design decreases. However, there is nothing wrong with that, and many things cannot be studied in an RCT at all. That is why we talk about "the best available evidence" and not just RCTs. Public health researchers should use methods further down the list if they are the best suited to answer their research question.

Practising evidence-based medicine

In the real and practical world, however, things are not always so easy. A doctor sees patients who are quite different from those who were involved in RCTs: they have other diseases (and maybe more than just one), they have other medication and there are often other complicating factors. The same applies to, for instance, evidence-based teaching – pupils and students are not always like those that were tested in a scientific study.

Things get even more complex in the real world of AIDS where many non-medical factors – such as poverty or traditional practices – influence the distribution and susceptibility of infection with the HIV virus. We have strong evidence with regard to some of these factors, such as the clear link between being poverty or a low level of education and HIV/AIDS, while with regard to others we have weak or no evidence. NGOs that wish to address the underlying causes of HIV/AIDS have to make use of the entire panoply of interventions and draw on lessons from the fields of communication, social behaviour, and health. There is often not much "hard evidence" in the biomedical sense to compare interventions that for example combine education, human rights, health, gender, poverty reduction and sexuality. These types of interventions are difficult to measure against any objective standards because they are bound to time and location. They must instead be assessed in their specific local context in order to draw conclusions about whether it might be useful to replicate them in another project.

Evidence-based public health

In public health, the above picture is further complicated. A typical programme aiming to improve the conditions of people in society does not include one single intervention, but a set of interventions. Each one should ideally have been found to be effective in isolation, in several societal "experiments" in different countries. But when choosing different interventions, which ones should be combined to act in synergy? And if we cannot afford the best ones, which of the second-best ones should we choose, ensuring that they work well together? And how should one balance acute needs against the needs of tomorrow, or of the decades to come? An infection, like HIV, that spreads among many people and causes devastating effects in entire societies constitutes a threat to world development. We must be reasonably sure that we are doing or planning to do the right things – and that we implement them correctly. The important thing is to have looked for and analysed the evidence before deciding on what to do. Otherwise, there is a risk of making poor decisions due to not knowing that there are better options to choose from.

"Evidence-based public health" is here to stay. But that does not mean that everyone adheres to it. It seems obvious that we must know which are the most effective interventions, and preferably which are the most cost-effective – and that they should be implemented together. These kinds of interventions are often publicised as "best buys" – the ones that will give the best impact for the least amount of money. But they are not always well known, and one of the aims of this manual is to present relevant interventions to non-governmental organisations working with HIV/AIDS. The specific focus has been on how to integrate HIV/AIDS activities with sexual and reproductive health interventions.

Public-health-oriented reviews are available at special websites or via search engines (see Box 28). The reviews available at the following sites are sometimes full-fledged systematic reviews and sometimes more superficial overviews. They do summarise

Box 28. Where to find public health evidence

- www.pubmed.net
- www.thecochranelibrary.org
- www.york.ac.uk/inst/crd/crddatabases.htm
- www.scirus.com
- www.scholar.google.com
- www.thecommunityguide.org
- www.hda-online.org.uk/evidence
- www.popline.org

current reviews and overviews but require critical selection and judgement. The assessment of what recommendations to use also depends on the context of any new project/programme contemplated.

The major development and health organisations use these reviews and other reviews that they themselves commission. Most of what today is officially put forward by e.g. WHO, UNICEF, UNFPA or UNAIDS constitutes the best available evidence.

NGOs and evidence-based interventions

In their daily work, NGOs are of course not to be measured against the same scientific standards as researchers that publish in peer reviewed journals. NGOs are, however, obliged to be able to explain whether their interventions have an effect on the target group they wish to reach. Doing a systematic literature review is often perceived as time consuming and 'too academic' by overworked NGO staff. However, it might be the only way to get up-to-date inspiration and solid arguments for a planned intervention. If an NGO is debating different types of interventions, it can be useful to take time to go through the following steps: 1) formulating an answerable question; 2) searching the overview literature and websites (such as the ones in Box 28) and organising available information; 3) making a choice based on evidence, values and available resources and external factors such as harmony with the national HIV/AIDS coordination mechanism. An example of such a question could be "What kind of HIV/AIDS education results in less infections in Senegal for urban, unmarried girls between 10 and 19? Is it peer education through youth clubs, school-based education or NGO counselling at youth friendly health services?"

NGOs can gain a lot in project effectiveness by setting up simple procedures to ensure that already existing systematic literature reviews are used, in order to build up expertise among staff members. With practice, this procedure becomes less time-consuming and more stimulating. Furthermore, NGOs can contribute tremendously to the refining of our common knowledge base about the HIV/AIDS pandemic and its linkages to SRHR by systematically reporting not only project success but also project failures or unintended outcomes. It is a moral obligation to share not only best practices but also unsuccessful practices.

Evidence is, however, only a basis for decision-making. Having established an evidence-based decision-making process within your NGO is, unfortunately, not a guarantee for maximum health benefits at minimum risk and cost. The outcome is determined by the quality of the management within the NGO and to some extent by externalities that the NGO cannot be held fully responsible for. When the technical staff has presented the available knowledge to the management, it is up to the management to provide the required resources and institutional support so that the project can actually be realised as intended.

B. How did we choose the substance for this manual?

The authors of this manual are acutely aware of the need to provide the readers with the best available evidence. In order to do this, we have taken the following steps:

I. Used current systematic reviews when available;

II. Drawn on the recommendations of WHO, UNICEF, UNFPA, UNAIDS and UNHCR and examined the basis of the evidence provided by them;

III. Selected a few representative references for each chapter, reflecting the evidence;

IV. Secured the critical input of select experts familiar with the global body of literature, experiences and current research in their field, for certain chapters;

V. Received the input of reviewers active in HIV/AIDS and sexual and reproductive health programmes in low-income countries and elsewhere.

In addition to the resources we provide, users of this manual should consider carrying out their own country or intervention-specific searches for evidence. One place to start is E-Roadmap to Evidence-Based Public Health Practice (http://www.publichealthsolutions.org). Here, and on similar websites, you can read more about what evidence in public health is, how to grade it and how to build your own skills in searching for relevant evidence.

The best-known place to look for evidence in the form of articles, is Medline. Medline has an online training programme that you can follow yourself (www.nlm.nih.gov/bsd/pubmed_tutorial/m1001.html). Furthermore, Aidsnet has developed its own easy-to-use domain for search and retrieval of scientific literature on HIV/AIDS in low-income countries. It can be found at www.search.aidsnet.dk

We encourage you to try out the abovementioned websites and search engines and send feedback to Aidsnet on what works for you, what you have found and what needs improving, to help all NGOs make the best possible use of evidence. This manual is only the first step. Good luck. ■

About the authors

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AIDSNET, the Danish NGO Network on AIDS and Development, seeks to help fight HIV/AIDS and promote sexual and reproductive health and rights in low-income countries. It believes that now is the time to take advantage of current international interest, funding, and mobilization levels to build an effective, comprehensive, evidence-based response to the AIDS crisis.

AIDSNET is an open member-based network of NGOs, research institutions, and resource persons working with HIV/AIDS in low-income countries. It is partly financed by Danish International Development Assistance (Danida).

Member organisations

- **ADRA Denmark**
  www.adra.dk
- **The AIDS Foundation**
  www.aidsfondet.dk
- **The AIDS Hotline**
  www.aids-linien.dk
- **AXIS**
  www.axisngo.dk
- **Care Danmark**
  www.care.dk
- **DanChurchAid**
  www.dca.dk
- **Danish Association for International Co-operation, MS**
  www.ms.dk
- **The Danish Council of Organisations of Disabled People**
  www.handicap.dk
- **The Danish Family Planning Association**
  (Sex & Samfund)
  www.sexogsamfund.dk
- **Danish Mission Council, Development Department**
  www.dmr.org
- **Danish Red Cross**
  www.redcross.dk
- **The Danish Youth Council**
  www.duf.dk
- **HIV Denmark**
  www.hiv-danmark.dk
- **DBL - Institute for Health Research and Development**
  www.dblnet.dk
- **Ibis**
  www.ibis.dk
- **Doctors Without Borders**
  (Médecins Sans Frontières)
  www.msf.dk
- **The Nordic Africa Institute**
  www.nai.uu.se
- **Save the Children Denmark**
  www.redbarnet.dk
- **Southern Africa Contact**
  www.sydafrika.dk
- **Ulandssekretariatet (LO/FTF Council)**
  www.ulandssekretariatet.dk
- **Ungdomsringen**
  (The National Youth Club Association)
  www.ungdomsringen.dk
- **University of Copenhagen, Department of International Health**
  www.pubhealth.ku.dk

www.aidsnet.dk

Aidsnet
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