POSITIVE PREVENTION

HIV prevention with people living with HIV

A guide for NGOs and service providers
“People living with HIV showing their faces in public. I remember when I first became aware that I was infected with HIV. I was very afraid that people in my community would come to know about my status. Later on, when I dared to show my face to my community, then my life got better.” Chet Thol

This photograph was taken by an HIV positive photographer in Cambodia as part of the Alliance participatory photographic project, Unheard Voice, Hidden Lives. Participants were given cameras and photographic training. With their new equipment and knowledge, they were asked to use photography to tell the story of their lives and those of their communities.

www.aidsalliance.org/unheardvoices

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Front cover photo: Eric Nachibanga, treatment support worker (see inside back cover for more details)
Acknowledgements

The International HIV/AIDS Alliance has been working at the forefront of the civil society response to HIV since 1994. During this time we have witnessed many courageous efforts of community groups in over 40 countries worldwide to mitigate the impact of AIDS and slow down the spread of HIV among the most marginalised and vulnerable in their community. With more people now aware of their HIV status and some benefiting from antiretroviral treatment, we are increasingly aware that people living with HIV have HIV prevention needs.

This guide has been developed by Alliance staff working in HIV prevention, programming and policy with organisations that are developing strategies and initiatives for HIV prevention for HIV positive people. The Communications team at the Alliance secretariat co-ordinated the design development and production of this publication.

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Frontiers Prevention Project

The Frontiers Prevention Project is a multi-country prevention-focused initiative which aims to slow the spread of HIV and support populations that are key to the epidemic in responding to the HIV related challenges they face. It focuses on low prevalence countries that are put at risk by growing epidemics, working specifically in Cambodia, Ecuador, India, Madagascar and Morocco.

Funded by the Bill and Melinda Gates Foundation, the project has made an important contribution to increasing knowledge of HIV and how to prevent it, improving access to and the quality of treatment for sexually transmitted infections, and the creation of community-based organisations and networks of people living with and affected by the virus.
Warangal, Andhra Pradesh, India. Peer educators at a Lodi (MSSS) meeting

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Introduction

The expanding provision of antiretroviral (ARV) treatment has brought a return to good health and new hope to many people throughout the world who are living with HIV. This ongoing achievement, coupled with the increasing numbers of people accessing HIV testing, brings a new challenge: meeting the HIV prevention needs of people living with HIV.

This guide is intended as a resource to help non-governmental organisation (NGO) staff and HIV service providers working across the spectrum of HIV prevention, treatment, care and support services to take steps towards integrating HIV prevention for, by and with people living with HIV. It is hoped it will also be of use both to individual people living with HIV and to their partners. The guide does not intend to discuss or review all HIV prevention strategies. Rather, it is a starting point from which to consider different strategies to assist NGO staff and HIV service provider organisations to support HIV positive people to live well with HIV and have safer sexual relationships within a full and healthy life. This guide focuses largely on the sexual transmission of HIV.

Why positive prevention?

More than 40 million people worldwide are now living with HIV. Only a small proportion of them know their HIV status and many people with HIV still do not have access to ARV treatment. The global commitments to reaching universal access to HIV treatment, prevention, care and support aim to close these access gaps. As more people become aware of their HIV status and access HIV treatment, greater efforts are needed to adapt or create HIV prevention programmes that meet the HIV prevention needs of people living with HIV.

Most prevention strategies to date have been directed towards people who are uninfected with HIV or who do not know their status, to prevent them from becoming infected. Few strategies and messages are designed specifically for HIV positive people. This needs to change.

What is positive prevention?

Positive prevention aims to increase the self-esteem, confidence and ability of HIV positive people to protect their own health and to avoid passing on the infection to others. It needs to be implemented within an ethical framework that respects the rights and needs of people living with HIV to enjoy sexual relationships, have reproductive choices and live a full and healthy life. Positive prevention needs a supportive legal and policy environment to protect the rights of people living with HIV – in particular their sexual rights.
Positive prevention is based on the realities and perspectives of people living with HIV. It acknowledges that they have the personal right to choose whether or not to have sex, and therefore need explicit information and practical support to ensure that the sex they choose is safer for both them and their sexual partners.

Positive prevention is focused on communication, information, support and policy change. It does not blame, judge or stigmatise. HIV positive people are individuals with varying needs and desires.

Positive prevention requires the meaningful involvement and participation of people living with HIV. This means not only giving support and information to individuals and groups of people living with HIV, but also ensuring their participation in planning how best to apply the strategies to their local context. Strong, well-resourced organisations of people living with HIV, as well as individual HIV positive activists, working in partnership with governments and service providers can offer the expertise that derives from the lived experience of HIV. They also give a face to HIV. Acceptance and involvement at community level can increase the self-esteem and confidence of HIV positive people to protect their own sexual health and avoid passing on HIV infection to others.

Positive prevention requires HIV service organisations, HIV support groups and NGOs to integrate positive prevention with existing HIV programmes. It is important that information and/or support around safer sex, re-infections, reproductive choices, the effects of ARV treatment, and safer injecting drug use is available in all settings. This should include medical centres, treatment delivery sites, family planning clinics, home-based care programmes and community centres.

Positive prevention promotes human rights. Rights to health, privacy, confidentiality, informed consent, freedom from discrimination must be respected at all times, alongside the duty to do no harm.

Positive prevention recognises that HIV is fuelled by inequalities in power due to gender inequality, sexuality, knowledge, societal roles and poverty. HIV prevention strategies must be developed without further stigmatising those marginalised in our communities.

Positive prevention places responsibility for reducing transmission of HIV with us all. Openness, communication and information about sex and sexuality are the most effective tools to reduce the spread of HIV.
Effective positive prevention requires information, training and support for HIV positive people, their partners and health care providers. Prevention efforts should focus not only on individuals living with HIV, their partners and families, but also should include those who influence or restrict the behaviour, options and choices of HIV positive people.

Key preventative behaviours such as safer sex and safer injecting are not possible when people do not have access to correct information, condoms, lubricants or clean injecting equipment. Successful positive prevention needs resourcing and support to ensure that people have access to the information, commodities and services they need.

As a result of our work in many countries with people living with HIV, we have developed 15 strategies to guide our understanding of positive prevention. The 15 strategies are grouped under four main themes to illustrate their interconnectedness and to underline the need to combine strategies. These strategies are not stand-alone, mutually exclusive or exhaustive. It is important to plan and implement them in combination. The choice of strategies will depend on the specific needs of the people with HIV with whom a service or programme is concerned, the local social and cultural context, resource availability and the capacity of the implementing groups. Some strategies are more relevant to NGOs and community-based groups, while others would be relevant to state health care providers or governments.

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Strategy 1:
Information, education and risk reduction

Let's talk about sex!
When people are tested HIV positive they usually experience many overwhelming feelings. These may include fear of death and illness, depression and fears about passing on the infection to a sexual partner or child. Many people feel nervous and unsure about how to disclose their status to their family, friends or sexual partners.

HIV service organisations and NGOs – especially voluntary counselling and testing centres – have an important role to play in supporting and counselling people who are newly diagnosed with HIV. Providing appropriate and sensitively delivered information will ensure that people living with HIV fully understand their condition and how to live a healthy, positive life.

Information on HIV transmission should form the basis of a better understanding of HIV and help with assessment of the risks involved in each situation. People living with HIV may stop having sex when first diagnosed for a number of reasons, but over time may regain their self-esteem, confidence or sexual drive and resume a sexual relationship. It is therefore essential that they have all the right information relating to re-infection and the possibility of passing the infection on to others before they reach this point so they are confident and prepared. Crucially, HIV positive people need to know that certain sexual activities are riskier than others, and that risk changes according to the HIV status of both partners. The provision of clear and factually correct information about HIV transmission is essential. It is the most important factor in supporting HIV positive people to make informed decisions about their sexual health and the sexual health of their partners.

Support groups play a significant role in promoting discussion on sex and sexuality. It is essential to ensure that accurate information is available in support groups so this can be shared and discussed among members of the group. Some people find it easier to talk about sex in private, so it is also necessary to provide a protective and confidential environment to enable individual and group discussions around sex and relationships to happen outside of support groups. Sometimes it is valuable to get the support of trained counsellors to deal with difficult issues that may arise during discussions.

Myths and misperceptions continue to surround people’s understanding of HIV and AIDS. For many people living with HIV, the opportunity to be accurately informed about issues such as safer sex, sexually transmitted infections (STIs), reproductive choices and condoms does not exist. HIV service organisations and community-based NGOs can play a vital role in the dissemination, display and distribution of information on HIV and AIDS, STIs, safer sex and condom use. All health care settings, especially HIV treatment sites, should provide relevant and accurate information about sex and preventing HIV transmission, as well as deliver HIV prevention counselling and prevention commodities such as male and female condoms.

Issues to consider
• Most people – even nurses and counsellors – find talking about sex very difficult. It is important to recognise that people with HIV continue to have sexual lives after an HIV diagnosis. Positive prevention services need to support open discussions about sex and relationships.
Individually focused health education and support

- It has been common in some settings for counsellors and nurses to tell HIV positive people that they should abstain from sex completely or just have sex with someone else who is HIV positive. This advice may not be helpful to their psychological health on the one hand and on the other hand may expose to them reinfection. It also does not help the majority of HIV positive people who continue to be sexually active, nor those who are in relationships with HIV negative partners and want to continue a safer sexual relationship. The role of health service providers is to ensure that HIV positive people gain the skills they need to negotiate safer sex and maintain healthy sexual relationships.

- People’s perceptions of risk can change when their health situation improves. A crucial moment to reinforce prevention messages is when people have been on ARV treatment for some time and are feeling better. Counselling and peer support can help people living with HIV deal with these changes and support protective behaviour when their health situation improves.

- Introducing referral systems during the process of information dissemination is essential to link HIV positive people with services that may be available for them, such as treatment education and adherence support, STI diagnosis and treatment, community-based support groups, harm reduction services and so on.

- The challenge is to empower people with HIV to explore and maintain ways of being sexually active that are full, satisfying and safe. Learning techniques to support consistent condom use and ways to have non-penetrative sex may help to achieve this.

- Counselling needs to help HIV positive people and their partners to identify and address barriers that make it difficult to practice safer sex consistently, such as the need for intimacy or fears of rejection.

Behavioural change workshop for HIV positive couples in Lusaka, Zambia, run by Catholic Ngombe Home Based Care.

“We tell couples to make their own decisions and we will support them. I see the couples who attend these workshops and they leave with hope. If these workshops were running at the time my husband was diagnosed he wouldn’t have died. He saw there was no cure and he had no hope – he gave up life. I told him I still had a lot of things to live for and I am still here. He always said that I thought I was right about everything and I still go to his grave and tell him I was right about this.

I want to reduce the incidence of HIV/AIDS. I hope for a cure and the re-assurance that the ARVs will never run out – that no one can take them away – until we have found that cure.”

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Guidance on the risk of STI/HIV transmission in different sexual activities

There are many different sexual activities that men and women, men and men or women and women may engage in to express and enjoy themselves sexually. Sexual intercourse involving penetration is only one of these. There are many more. When assisting clients to assess their risk and make a risk reduction plan, it is important to help them to talk about what activities they engage in or can envisage. In this way, they will be aware of the risk level of all potential activities and, where possible, take steps to reduce these for themselves and their partners.

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<th>Safe sex</th>
<th>Safer sex</th>
<th>Unsafe sex</th>
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<tr>
<td>Sexual activities that could not involve semen, vaginal fluids or blood going from one person into another present no risk of HIV transmission. These include:</td>
<td>Sexual activities where semen, vaginal fluid or blood may be present, but where all steps are taken to prevent them from being exchanged. These include:</td>
<td>These are high risk sexual activities:</td>
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<tr>
<td>- Massage</td>
<td>- Masturbation of each other if there are no cuts on the hands and people don’t touch their own genitals afterwards</td>
<td>- Any practice with any person that allows blood, semen or vaginal fluids inside the body through the mucous membranes of the mouth, vagina, penis or anus or through broken skin</td>
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<tr>
<td>- Hugging</td>
<td>- Open mouth kissing if both partners have no bleeding gums or cuts in the mouth</td>
<td>These include:</td>
</tr>
<tr>
<td>- Solo masturbation</td>
<td>- Vaginal intercourse with a condom</td>
<td>- Vaginal and anal intercourse without a condom</td>
</tr>
<tr>
<td>- Body-to-body rubbing (not genitals)</td>
<td>- Anal intercourse with a condom and plenty of water-based lubricant</td>
<td>- Any type of blood contact, including menstrual blood, semen or vaginal fluid entering breaks in the skin</td>
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<tr>
<td>- Sex talk, sexy dancing</td>
<td>- HIV and oral sex (see below)</td>
<td>- Sharing sex toys without cleaning them between partners</td>
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<tr>
<td>- Sharing sexual fantasies</td>
<td></td>
<td>- Any type of sex that damages the delicate tissues in the vagina, head of penis or rectum; for example, dry sex, rough sex, abrasive substances in vagina</td>
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<tr>
<td>- Body kissing</td>
<td></td>
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<tr>
<td>- Showering together</td>
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<tr>
<td>- Using sex toys without sharing them</td>
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HIV and oral sex (mouth-to-genital contact)

Research has shown that it is possible to transmit HIV through oral sex, but cases where this has happened are rare. Opinions differ, but it is generally considered that receiving oral sex is safer than giving oral sex. The risk of HIV transmission through oral sex is greater if the person or partner has an untreated STI such as gonorrhoea or syphilis. Untreated STIs are easily transmitted through oral sex.
Let’s talk about pregnancy!

HIV positive women and men have the right to choose for themselves whether they want to have children or not. Couples who want to have children should be able to access the medical care and social support they need in order to have safe, healthy pregnancies and healthy babies born without HIV.

Information on risk reduction strategies during pregnancy, childbirth and breastfeeding should be made available for HIV positive people who may consider having babies. In many countries this is now done through prevention of mother-to-child transmission (PMTCT) services that are usually linked to district or central hospitals. NGOs and HIV service organisations increasingly play a central role in raising community awareness of and engagement in PMTCT services. Equally, in many countries a large number of women first find out they are HIV positive through antenatal testing programmes. While this can be a very stressful time for women, these programmes are in place to ensure that HIV positive women are offered the right care and support during their pregnancy, and all necessary steps are taken to reduce the chances of their baby being infected with HIV.

Information on the following options needs to be available:

- conceiving a baby when one or both partners are HIV positive
- avoiding pregnancy – availability of and access to contraceptives
- reducing risk during pregnancy
- reducing risk during childbirth
- reducing risk during infant feeding
- maintaining good health of the mother after childbirth.

Issues to consider

- Availability and quality of local PMTCT services.
- Availability and quality of local family planning clinics with staff who have been trained in HIV care and support.
- Opportunities exist for HIV positive people to discuss reproductive choices. These may exist in HIV treatment centres, family planning centres, voluntary counselling and testing centres and HIV service organisations. Discussing the choices available is an important step for HIV positive couples who are considering having a baby in order to protect the health of the mother and reduce the chances of HIV transmission to the baby.
- Some HIV positive women find it useful to discuss their questions and thoughts about having babies with other HIV positive women. Community support groups can often provide this opportunity.
- HIV positive women need support and information in order to take ARV treatment during pregnancy. Many are worried about the effects of the drugs on the baby. Some HIV positive women fear others will find out about their HIV status if they take ARV treatment. Counsellors and people who provide information on ARV treatment need to be aware of these issues and be prepared to discuss them with pregnant HIV positive women.
- Male partners need to be involved in discussing options for safe conception, pregnancy, delivery and breastfeeding.
Strategy 2:  
Post-test and ongoing counselling

Many factors influence an individual’s response to a positive HIV test result. Many HIV positive people find the process of post-test counselling an important intervention. It provides a crucial opportunity to give newly diagnosed people information about the meaning of their test results and about preventing HIV transmission. Some need long-term counselling to cope with the difficulties of living with HIV. Others do not receive any type of counselling or do not want to receive counselling. Whatever decisions people may take, those who receive counselling after testing are generally better equipped to protect themselves and to cope with living with HIV than those who do not receive counselling or support after diagnosis. HIV service organisations, NGOs and HIV support groups all play a crucial role in post-test counselling and in providing a community referral link to treatment centres and support services.

Post-test counselling provides the first opportunity after diagnosis to discuss emotions, health concerns, treatment, sex, sexual relationships and other issues that affect people’s daily lives. In these sessions counsellors emphasise issues such as living healthily, eating well, getting early treatment for illnesses or ARV treatment if necessary or available, preventing and treating STIs, practising safer sex and using condoms. Post-test counselling also offers an opportunity to make referrals to prevention, care and support services.

Post-test counselling offers many benefits for HIV positive people, including:

- greater ability to deal with the problems of living with HIV
- support with strategies to protect their own sexual health and the sexual health of others
- better understanding of how to access HIV care, treatment and support services, and referrals to those services.

Where the opportunity exists, ongoing one-to-one counselling integrates a number of formal and informal approaches to help individuals living with HIV to cope. It can provide a safe and private space for HIV positive people to discuss issues that affect their lives, such as disclosure of their HIV status, difficulties in negotiating safer sex, pregnancy, drug use and so on.

Ongoing group counselling is an alternative to one-to-one counselling that also facilitates mutual support. Members of the group discuss ways to reduce risk and incorporate safer sex strategies into their lives, and the disclosure of HIV to sexual partners. Increasingly, trained HIV positive people facilitate this type of peer group counselling for other people living with HIV.

To support one-to-one or group counselling sessions, many HIV service organisations and NGOs have developed information, education and communication materials specifically for HIV positive people. This is a useful intervention in many settings, allowing HIV positive people to take home a pamphlet or booklet that they can refer to as the need arises.

Issues to consider

- People living with HIV play a vital role in facilitating peer counselling sessions, using their experience of living with HIV. It is important to ensure that HIV positive people are well trained, receive the support they need to play this role and are properly remunerated.

- As with HIV testing, many people are reluctant to access counselling even when it is available. This is especially true of highly stigmatised populations such as sex workers, men who have sex with men, injecting drug users, refugees and young people. Counselling services must be developed in ways that respond to the specific needs of these groups. Strategies to raise awareness and promote uptake of counselling services need to include outreach and peer-based methods to mobilise and engage marginalised communities.
Individually focused health education and support

- Counselling needs to be part of good referral pathways to community organisations and structures such as post-test clubs, NGOs, community-based organisations, private and public health providers, traditional healers, groups of people living with HIV, churches, businesses and trade associations.

- Health care workers are often in need of training and sensitisation to the needs and rights of HIV positive people from marginalised communities. Many HIV positive people experience significant stigma and discrimination in health care settings, and training of health care workers about HIV and HIV-related discrimination helps to overcome these problems.

Case study:
The Mexican Network of People Living with HIV/AIDS at Clínica Condesa, Mexico City

The Rubén Pérez Silva Care Centre was initiated in 2000 by the Mexican Network of People Living with HIV/AIDS in order to generate a culture of solidarity between people who had access to treatment and those who did not. The Care Centre is located inside Clinic Condesa, a specialised clinic for HIV/AIDS created by the local government in Mexico City. Clinic Condesa offers HIV testing and counselling, psychological support, ARV treatment and AIDS care.

Initially, the centre concentrated on collecting medicines from people who had stopped taking treatment for various reasons and redistributed them among those who did not have access to treatment through the social security scheme. Later, they incorporated treatment literacy, adherence support, peer support and counselling for HIV positive people who attend the clinic. Prevention became part of their work in response to recurrent issues for service users, such as:

- obstacles to re-initiating a sex life after an HIV positive diagnosis
- safer sex and sexual pleasure
- guilt and shame related to sex and sexuality
- fear of passing the infection to others
- fear of talking to the doctor about STIs
- lack of knowledge/skills to identify STIs
- lack of skills to negotiate condom use
- difficulties in disclosing HIV status with sexual partners
- lack of skills to maintain safer sex.

The team designed a set of strategies to begin to address some of these issues:

- Training workshops on sexuality and HIV; STIs; condom and lubricant use; disclosure; and strategies to identify and confront internal stigma. These workshops run over a six-week period.
- Peer counselling, including individual sessions using active listening and strategic questioning, information and ongoing support for behaviour change.
- Support groups, providing a safe space for HIV positive people to meet, share experiences and get support from each other.
- Distribution of condoms and lubricants at the care centre and at meeting places.
- Referrals to other services and institutions, including sexual and reproductive health, STI diagnosis and treatment, voluntary counselling and testing, and legal advice on anti-discrimination law and human rights violations.

The involvement of people living with HIV in prevention is essential to support other HIV positive people to deal with issues related to guilt and blame and to promote protective sexual behaviours. Individual peer support sessions have helped users to understand the problems, build skills and confidence to talk about STI symptoms with health care providers, and recognise the importance of early detection and treatment of STIs.

“I worked in groups on this idea of prevention ... The main principle is to help people to become responsible for themselves, their bodies and their rights. When people become aware of their situation it is possible to promote change.”
– HIV positive service provider
Strategy 3: 
Counselling for sero-discordant couples

Counselling and support services need to look at new ways of supporting couples who do not share the same HIV status.

Counselling sessions for sero-discordant couples offer an additional way to provide support to people with HIV. Working with couples to deal with the difficulties posed by a positive test result, and planning strategies to reduce risk, can be a very supportive intervention. This type of counselling helps sero-discordant couples talk about sex, plan strategies to reduce risk and discuss pregnancy and parenting desires and options.

In some countries, pre- and post-test counselling is provided automatically to couples. This can be an effective tool for avoiding scenarios where the partner who receives a positive result is blamed for the result. Couple counselling is also a good setting in which to introduce the idea of condom use and to provide support to the HIV negative partner to cope with the situation. In countries with high gender inequalities, this kind of intervention can support women to consider the safer sex options open to them and plan strategies with their partners to reduce risk.

Issues to consider

- It is more difficult to promote counselling for couples in societies where there are cultural taboos that impede open discussion about sex and sexuality. Couples may be reluctant to attend counselling sessions together, and as a result it can be difficult to implement this strategy. It is important to work closely with communities and provide contextually sensitive alternatives to deal with these obstacles, such as organising post-test clubs or support groups for couples, and engaging traditional leaders, headmen or church leaders as “gatekeepers” of gender and community norms.

- There are many barriers to maintaining consistent condom use, including local taboos and myths; the desire for sexual intimacy and trust, and perceptions that condoms interrupt this intimacy; drug and alcohol use; and inability to negotiate condom use. Counselling cannot always overcome these barriers. Counsellors should be prepared to deal with these and other difficulties.

- Health care providers play an important role in supporting sero-discordant couples and promoting discussions on the role of non-positive partners in supporting adherence to treatment, decision making on pregnancy and parenting, or more general discussions about sex and sexual health.

Village near Battambang, Cambodia

Soem Touch is a traditional singer, drummer and comedian and works together with his wife, Lika, who is also a singer. They married eight years ago and have two children.

In 2004 Soem Touch was told he was HIV positive. He had tested positive two years before, but the doctor didn’t tell him, although he disclosed his status to other patients in the hospital. Soem Touch believes that the lack of ethical standards is a big problem confronting PLHA in Cambodia and stops people testing in the first place.

Several months after their first baby was born Lika too tested positive and both are now receiving treatment.

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Strategy 4: Dealing with disclosure

Disclosure of HIV status can be an affirmative and empowering action that helps people receive support and understanding, and gain confidence to live well with HIV. For others, it can seem – and often is – an impossible option due to fear of violence, rejection or discrimination. Decisions around disclosure are intrinsically personal and often linked to gender inequality, power relations, economic dependence, fear of prosecution due to sexual orientation or drug use, and family dynamics. Many people who decide to disclose do so only to a very limited number of trusted people and not necessarily to any or all of their sexual partners. The quality and quantity of counselling HIV positive people receive after the diagnosis can affect their willingness to disclose to significant others. While individual circumstances differ, people with HIV who are well supported may feel more able to disclose over time.

HIV positive people who disclose their status may do so at different levels and for different reasons. These levels are linked, and could include disclosure to:

- family and/or friends for support
- sexual partners (casual and/or long-term)
- organisations and service providers in order to receive treatment, support and information
- give support and information and to help other people.

The reasons may include:

- feeling isolated
- feeling depressed
- feeling anxious and alone
- needing support
- caring for and protecting sexual partners.

People living with HIV have developed some useful strategies to support people to decide why, when, how and to whom to disclose their status. When planning to offer support to deal with disclosure, it is important to prepare the person to consider the range of possible consequences, both positive and negative. This can be done using techniques such as role-play. For example:

- Who do you want or need to tell about your HIV status? Why do you want them to know?
- What will they do with the information once they know?
- Will they maintain your confidentiality?
- How much are you ready to share? Is the person you want to tell ready to hear?
- How will it affect the person you tell?
- How will they cope?
- Who can they turn to for information, support and advice?
- When and where should you tell them?

Issues to consider

- HIV positive people have the right to choose who, how and when they tell about their status. Advising all people to disclose always can have many negative consequences.

- In some communities women have more to lose than men. Many women do not disclose their status for fear that their children will be discriminated against in school or in their community. Many women fear domestic violence or have experienced domestic violence as a result of disclosing their status to their partners. It is important to understand that disclosure to just one or two people and not to members of the family is an alternative for many people who want to protect themselves and their families from harm.

- Strategies to promote disclosure should be supported by community education and advocacy efforts to ensure that laws and policies are in place that protect HIV positive people against discrimination and that promote confidentiality and privacy.
Ensuring access, scaling up and improving service delivery

Strategy 5: HIV testing and counselling

Today it is estimated that close to 40 million live with HIV – yet the vast majority are unaware of their status. (*Report on the global AIDS epidemic, UNAIDS 2006*). This situation continues to have a profound effect on HIV prevention efforts for both HIV negative and HIV positive people. Early diagnosis of HIV infection enables HIV positive people to have greater control over their health. However, there are many barriers to testing, often related to fears about HIV and AIDS, the stigma associated with HIV and the ensuing discrimination that HIV positive people commonly face. Many expect that the greater availability of quality voluntary counselling and testing services and access to ARV treatment will decrease fear of HIV and increase uptake of HIV testing, as more people recognise the benefits of knowing their status and beginning treatment.

Provider-initiated HIV testing is a growing method of testing whereby a health care worker routinely offers an HIV test to a patient attending a clinic with any health concern. That person is then explicitly given the right to opt out of the HIV test. Provider-initiated testing is an attempt to increase the number of people tested for HIV given the high rates of HIV positive people whose status is undiagnosed. In countries or districts with high HIV prevalence, provider-initiated testing may be a cost-effective approach. In places with low prevalence or epidemics concentrated among particular sub-populations, it is unlikely to be cost-effective. But wherever provider-initiated testing is occurring, it must be done with care and attention to the rights of people to opt out of a test without experiencing any penalties, denial of service or other harms. People routinely offered a test also have the right to basic information about HIV along with information about the implications of an HIV test. People must explicitly give informed consent. Most importantly, people who are routinely offered an HIV test and who test positive should be offered support and protection from stigma, discrimination and violence, must be guaranteed privacy and confidentiality, and be referred to HIV treatment and support services. Provider-initiated testing must not 'cut-short' the rights of people living with HIV.

People test for HIV when it makes sense for them to do so. Therefore it is important to work towards increasing the number of reasons for people to come forward for testing. Availability of ARV treatment is a major reason. Ensuring that HIV testing and counselling are conducted within an ethical framework that respects confidentiality and privacy and ensures truly informed consent are vitally important requirements.

HIV testing and counselling provides benefits not only for those who test positive but also for those who test negative. Pre-test counselling helps people to understand how HIV is transmitted, to assess their own risks, practice safer sex and take steps to avoid STIs. Through post-test counselling, people can be referred to other services, such as STI care, family planning, individual/couple counselling, post-test clubs, treatment for opportunistic infections, ARV treatment and PMTCT services. Good referral systems within counselling and testing services are crucial to ensure that people receive the support they need, irrespective of test results.

**Issues to consider**

- As the number of testing and counselling sites increases, it is essential to ensure quality. The establishment of networking opportunities to share experiences among testing providers, improve referral systems and promote best practice can support quality standards in testing.

- In some places it is difficult to recruit enough trained counsellors to respond to the increasing demand for testing. UNAIDS (2002) provides suggestions on how to incorporate different kinds of counsellors, with different roles, training and responsibilities. People living with HIV can become peer counsellors, drawing on their own experiences. Non-health care workers can be trained in rapid test kit use, lay counsellors can be employed, and specific courses on HIV testing can be provided and accredited, avoiding the need to recruit qualified generic counsellors, psychologists or social workers. It is important to provide training.
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Strategy 6: Treatment and care

The introduction of ARV treatment not only prolongs lives but also improves the quality of life of people with HIV. Many people are still alive because they have the opportunity to access ARV treatment. But ARV treatment is only beneficial when people adhere to their treatment regimes on a daily basis for the rest of their lives.

In many countries adherence to treatment remains a huge challenge. Many factors affect a person’s ability to adhere to their treatment regime, including not having disclosed to their family members; needing to take their medicines in secrecy; sharing their medicines with other people they think are HIV positive; not being able to afford transport costs to go to the clinic to ensure a regular supply of medicines; feeling unwell; not having access to drug substitution therapy like methadone, and not having sufficient food to take with the medicines. NGOs and HIV service organisations can play a vital role in supporting adherence through home and community-based activities and outreach. In some places, people living with HIV or family members are playing the role of treatment supporters, providing information and support to HIV positive people to aid their adherence to their ARV treatment.

The benefits of treatment also depend on the ongoing availability and uninterrupted supply of quality medications for a lifetime. It is imperative to ensure that people who start ARV treatment do so as part of a sustainable programme that ensures availability, continuity and quality of the treatment for as long as it is needed.

One of the first effects of ARV treatment is reduction in the level of virus in the blood (or viral load). It is essential for HIV positive people to understand that even if this is the case they can still pass on the HIV infection to another person. Two factors complicate the relationship between viral load and infectiousness. First, HIV can be present in other fluids apart from blood in different quantities; for example, semen or vaginal fluids. Second, viral load can rise and fall over time, even in the course of a day. These two factors demonstrate the need to begin and maintain safer sex and safer injecting practices.

Issues to consider...(cont'd)

for counsellors who may find it difficult to talk about sex and sexual relations.

- Pre-test group counselling offers a further alternative in situations where there are too few counsellors. Pre-test counselling is first provided to a group of people and then the decision to go for testing (or not) is made on an individual basis. Post-test counselling is only provided on an individual basis. Group counselling prior to a test offers an alternative way to deal with the needs of specific populations, such as men who have sex with men, injecting drug users or sex workers, or in health care settings such as antenatal clinics.

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Supportive interventions can include:

- providing information on ARV treatment, including the nature and names of medicines, the number of pills per day and the importance of taking the medicines daily at regular intervals
- providing peer support to people who find it difficult to take their medicines on a regular basis and planning personal strategies for overcoming these difficulties
- reinforcing HIV prevention messages when discussing treatment, including discussion of safer sex, reproductive options for people who want to conceive, and early detection and treatment of STIs and other infections
- providing information on services available in the community, such as sexual and reproductive health care, STI diagnosis and treatment, family planning and harm reduction programmes for people who inject drugs
- advocating for a regular supply of ARV treatment that ensures people will receive treatment without interruption and that quality will be maintained
- promoting peer networking and peer support to share personal adherence strategies
- developing family-centred adherence strategies for households with HIV positive or negative children.

Issues to consider

- It is important to ensure clear information about ARV treatment for all households, communities and people with HIV to avoid misunderstandings and to clarify the complex issues around treatment. Information should include basic facts on the type of treatment available, the need for high levels of adherence, the side effects of taking treatment and the need for good nutrition.

- Some studies point to behaviour change as a result of ARV treatment. “Treatment optimism” is the term applied to the phenomenon of false perceptions arising out of treatment success, leading to a “relaxing” of safer sex practice. The extent of this problem is unknown, but concerns about the potential for treatment optimism underlines the importance of constant and comprehensive strategies for positive prevention to address false perceptions about ARV treatment and infectivity.

  The relationship between the health care worker and the patient is essential to ensure that people understand their treatment and follow the prescription they have received. Health care workers and peer treatment supporters can support people to understand their medications and take them regularly. Treatment services provide vitally important opportunities to reinforce positive prevention.

The Positive Women’s Network in Zambia is a support group specifically for HIV positive nurses. Despite their awareness of ARVs and exposure and acceptance of HIV and AIDS in their patients, many continue to conceal their positive status, and are thought to care for others much more readily than they care for themselves.

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Strategy 7: Prevention supplies and commodities

When people start taking ARV treatment they need to go for check-ups and to collect medicines at regular intervals. These regular contacts with an ARV treatment delivery site (hospital, care centre, mobile care unit, home-based care team) provide a good opportunity for offering condoms and lubricants and reinforcing positive prevention efforts through care services.

Making available male and female condoms and lubricants at ARV treatment sites will ensure that people who need them not only have access to them but also receive information on how to protect their own sexual health and protect others.

Similarly for injecting drug users who are on ARV medication, treatment sites are an opportune location for them to access clean syringes and other injecting equipment.

Issues to consider

- Availability, access and affordability of male and female condoms and lubricant. Organisations that specialise in social condom marketing and free condom distribution can work together with health clinics to ensure a reliable supply of condoms and that wider distribution is achieved.

- Correct and consistent condom use is essential for people living with HIV. This information should be made widely available in health care facilities and ARV treatment delivery sites.

- Promoting condom use among stable couples can be challenging. Couples who may assume it is too late to adopt safer sexual practices must be encouraged and supported to use condoms through ongoing counselling. Health care facilities need to be linked to counselling services in order to support HIV positive people to make good-quality risk assessments of different sexual behaviours and to promote ongoing condom use.
Strategy 8: Developing referral systems

Referral systems need to be in place to ensure that people benefit from all the services available in the community. An important first step is to know what services and community organisations exist and how to access them. A map of all these services should be made available for health care providers and for people living with HIV.

There are a number of basic services that need to be linked for the benefit of HIV positive people, including:

- testing and counselling services
- primary care or NGO clinics for HIV, including treatment for opportunistic infections
- peer support groups and post-test clubs
- income-generating groups or micro-credit organisations
- orphan or vulnerable child support services, including those that assist with school fees
- home-based care programmes and those involved with food distribution to vulnerable households
- sexual and reproductive health services, including STI diagnosis and treatment and contraceptive advice
- PMTCT services
- suppliers of condoms and injecting equipment
- drug substitution treatment services for injecting drug users.

Issues to consider

- A referral system works best when the care providers are familiar with both the nature and the quality of services provided by each facility in order to make appropriate referrals. The experience of people using the services should also be considered in assessing and improving the quality of services.

- It is important to ensure a two-way referral system from community to health care services and back to the community. Availability of a pamphlet listing all the services that can be accessed in a particular community may help maintain a good flow in the referral process.
Case study:
The Cellules: Ensuring availability of services for positive people outside Dakar, Senegal

Created in 1997 with the support of the Alliance Nationale de Lutte Contre le Sida (ANCS) in Senegal, the Cellules are a particular type of community-based association that has enabled prevention, care and support services for people living with HIV to be decentralised to several regions in Senegal. These Cellules are multidisciplinary teams of health care providers, social workers, peer educators and people living with HIV. The aim of the Cellules is to facilitate access to a comprehensive range of prevention, care and treatment services for people living with HIV at regional and local levels.

The Cellules provide the following services to people with HIV:

- post-test counselling
- psychological support for people receiving positive test results, during office consultations or home visits
- material support to HIV positive people who need it, in particular free medications
- professional and social inclusion of people living with HIV through loans to finance income-generating activities
- support groups for people with HIV
- meetings between HIV positive people who receive the services and members of the Cellules to share experiences and to update and improve information used by all parties
- information, education and communication campaigns for the general public
- referral services for people living with HIV.

The Cellules act as catalysts to facilitate and strengthen the collaboration of the various actors involved in HIV work, including health care providers, social workers, peer educators and people living with HIV.

This collaboration has had many advantages:

- It has eased the referral process between various sectors and enabled the provision of a comprehensive range of prevention, treatment and care services for people living with HIV.
- As a result of improved communication between people living with HIV, doctors and social workers, preconceptions about people with HIV have changed and professionals have a better understanding of the needs of HIV positive people.
- This approach has promoted the integration of prevention, treatment and care services, including counselling services, support groups and information, education and communication activities with the community.
Strategy 9: Facilitating post-test clubs and other peer support groups

Post-test clubs and peer support groups offer a private and safe space to help people to cope with HIV by sharing experiences and providing mutual support.

Post-test clubs are usually linked to counselling and testing services, and could be developed in association with them. These clubs are set up for people after they have been for an HIV test. They provide ongoing counselling and support services. Both HIV positive and HIV negative people can join the club for a specified or unlimited period of time. Some clubs provide activities for the community, such as outreach HIV education, drama and dance.

Some support groups are only open to people living with HIV, and provide a confidential space where they can share their experiences of living with HIV and discuss important issues such as disclosure, sex, financial concerns, income-generating opportunities, nutritional advice or ARV treatment adherence. Group activities may include informal sessions to share personal experiences or formal sessions where speakers are invited to talk on a particular issue.

The activities that support groups may offer include:

- ongoing counselling and group therapy
- HIV education through lectures, drama, music and dance
- positive living programmes
- medical treatment
- HIV prevention case management (this type of programme is offered on an individual basis to support HIV positive people to assess their needs, develop a plan to address some of these needs and facilitate access to other services or resources)
- income-generating activities
- social support network and personal development.

Issues to consider

- In high-prevalence countries, post-test clubs have proved effective in reducing stigma related to HIV at community level. In countries where the epidemic is concentrated in specific groups, care should be taken to ensure that post-test clubs do not draw negative attention, increasing stigma and discrimination towards groups already marginalised in society, such as people living with HIV, injecting drug users, men who have sex with men, and sex workers.

- Women living with HIV often need particular support and may prefer to discuss some issues only with other HIV positive women. The creation of HIV positive women-only support groups can help women discuss issues such as how to get their men to practise safer sex; how to disclose their status to partners or children; pregnancy and breastfeeding; and how, when and where to ask for home-based care or to organise income-generating activities to ensure household security.

- Specific support groups for injecting drug users have also proved essential in order to create safer spaces for former or active users. Some of these groups may be connected to needle exchange and methadone substitution programmes in countries where these are available.

- Support groups for specific populations such as HIV positive sex workers or HIV positive men who have sex with other men are important for creating safe spaces where they can meet together and develop networks of mutual support. They also can become a platform for advocacy aimed at improving services, highlighting human rights abuses and participating in decision making.
Case study: SPOORTHI: Inspiration from Vasavya Mahila Mandali in Andra Pradesh, India

Vasavya Mahila Mandali (VMM) is a voluntary organisation established three decades ago to work on issues related to women and children in the coastal area of Andhra Pradesh, India. VMM runs a home and community-based care and support programme in the informal settlements of Rajiv Nagar and Kandrika. In particular, VMM provides support to HIV positive women through HIV positive women’s groups and one-to-one counselling services. The support groups conduct bi-monthly meetings, where HIV positive women can meet and share knowledge. These groups offer a safe space where women can analyse their potential HIV risk and discuss protective behaviours. The main messages are positive living, condom use, reproductive health and partner reduction.

In a sensitive environment, VMM has faced up to the challenge of addressing sexuality and promoting safer sex with HIV positive women in a way that is culturally acceptable to the women and the community.

Key strategies include:

- creating women-only support groups
- integrating safer sex into a “self care” curriculum, where the issue of sex and sexuality is approached as part of a self-care programme
- addressing general health and nutritional issues as the starting point and then moving on to discussions about sex and sexuality
- providing comprehensive information on condom use and specific advice about safer sex in follow-up one-to-one sessions
- offering counselling services to tackle sensitive issues
- training HIV positive women as speakers who are able to talk confidently about condom use and partner reduction to women’s groups and communities in order to tackle stigma and discrimination
- providing free condoms.

VMM approaches sex and sexuality in ways that are culturally acceptable and that promote the voices of HIV positive women.
Strategy 10:
Training HIV positive people as peer educators and counsellors

HIV positive people have an important role to play in working with community leaders and decision-makers to reduce the stigma associated with HIV and AIDS. There are many examples where HIV positive people have acted as role models, giving a face to the epidemic and helping to reduce fear and shame in their communities. But HIV positive people also need training and support, including income support, to ensure they have the skills necessary to perform these tasks optimally.

Many HIV positive people are willing to work with their communities as peer educators, members of home-based care teams or counsellors. However, they do not always receive training and support to build their confidence to perform these tasks well. It is important to create training opportunities for HIV positive people, enabling them to act as:

- outreach peer educators, offering basic information on HIV and information on living positively with HIV
- peer counsellors for positive prevention, supporting HIV positive people to make informed decisions on healthy sexual relationships
- peer counsellors in treatment, supporting people on ARV treatment (or about to start treatment) to deal with issues of adherence, nutrition, side effects and treatment options during pregnancy.

Issues to consider

- There is an assumption that the experience of living with HIV is a sufficient basis for becoming a community worker. Many HIV positive people have gone through very difficult times and need support to rebuild their confidence before taking on the role of a community worker. Lack of formal education should not be an obstacle to training or to operating as peer counsellors. There are many ways of offering information and support that do not rely on the use of printed materials. For example, in Khayelitsha, South Africa, the Mothers 2 Mothers 2 Be programme (see below) is supporting HIV positive pregnant women to make decisions about safe motherhood through peer counselling. HIV positive women who have recently had HIV negative babies share their experiences with pregnant women in the waiting rooms of antenatal clinics and provide information on safe delivery and breastfeeding.

- Training for peer counsellors and peer educators should include support to cope with the stresses of this challenging work. Ongoing supervision is also important to ensure that information provided is up to date and accurate.

- Personal testimonies by HIV positive speakers can be powerful vehicles for HIV and AIDS awareness raising, and may help to reduce stigma and discrimination. But people need support and encouragement to speak publicly.

- People living with HIV may be effective community educators, but they should be remunerated adequately, financially or in kind.
Case study: 
Mothers 2 Mothers 2 Be (M2M2B) in the Western Cape Province, South Africa 

Mothers 2 Mothers 2 Be (M2M2B) is a mentorship programme designed to link recently delivered HIV positive mothers with HIV positive pregnant women. Pregnant HIV positive women receiving prenatal care are paired with HIV positive women who have recently completed prenatal care and delivered their babies. These new mothers act as mentors for the pregnant women for the duration of their pregnancy, educating and counselling them during prenatal visits. This mentoring programme also helps HIV positive women to adhere to ARV treatment regimens, it ensures regular attendance to hospital visits and it helps HIV positive pregnant women deal with stigma and discrimination.

The first-hand experience of mothers who have recently made similar decisions helps other pregnant women to make good decisions on ARV treatment during pregnancy, breast- or bottle-feeding, Caesarean section or vaginal delivery and sterilisation of injections for birth control. This ongoing support for HIV positive pregnant women not only improves their sense of well-being but also empowers them to make good decisions for themselves and their babies.

“Through M2M2B we see women who had been grim now smiling. We find women who had sat alone (during prenatal visits) now sitting with others and talking. Women in the past had waited hours to be seen, without any interaction. Now we offer them lectures and discussion groups. We are creating an environment that celebrates life, enhances the power of positive thinking and action, and encourages women to think of themselves as strong rather than victims.” – Volunteer obstetrician working on the programme in 2002

Maria, a sex worker, leans from the window of her work room to greet her son and his friend. Maria takes part in peer education sessions on sexual health and regularly gets herself tested for HIV.

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Strategy 11:
Reinforcing positive prevention through home-based care

In many communities, particularly rural communities, home-based care is the only way possible to ensure that people living with HIV receive treatment and care on a regular basis. Home-based care is an important intervention to promote HIV prevention efforts for HIV positive people. It provides important opportunities to promote safer sex and to refer to STI diagnosis and treatment and PMTCT services. The visibility of home-based care and support also offers a powerful challenge to stigma and discrimination, and encourages community acceptance of HIV.

The types of activities that should be carried out by home-based care team members include:

• promoting safer sex information, education and counselling
• providing information on personal risk reduction strategies
• distributing condoms, lubricants and clean injecting equipment
• linking individuals, families and households to other community services, such as family planning, support for school fees, food distribution and income generation services
• HIV prevention services (information, education, counselling, condom distribution, referrals to services) to other members of the family and community.

Issues to consider

• Home-based care team members and volunteers need to be well supported to ensure they have the skills and resources needed to provide prevention, treatment, care and support services, including accurate information on HIV prevention, safer sex and sexual health.

• Appropriate training and support should be offered to every member of the home-based care team, and in particular to people living with HIV who form part of the home-based care team.

Case study:
Home care programme of Khmer HIV/AIDS NGO Alliance, Cambodia

In Cambodia, a recent programme evaluation found that Khmer HIV/AIDS NGO Alliance (KHANA)’s home care programme is having a significant positive impact at a number of levels:

• It is reducing the suffering of people living with HIV and improving the quality of their lives and those of their families and caregivers.
• It is increasing their understanding of HIV by helping to forge links between care and prevention and reducing stigma and discrimination against people living with HIV in the community.
• By providing social and economic support, it is helping to empower some of the poorest and most disadvantaged individuals and families in the community.

The wide reach to people living with HIV and the trust developed mean that the KHANA home care programme is well placed to provide prevention information and services, such as supplying condoms. A majority (83%) of community leaders interviewed reported that the KHANA home care teams were helping to increase understanding of HIV prevention messages. The effect on neighbours of awareness-raising and challenging HIV stigma was also identified:

“People didn’t believe we had AIDS here. Now they are more brave in talking about condoms. Before, their knowledge about AIDS was just from the television. The home care team have brought them the reality.” – Village headman, Cham Carmon, Phnom Penh

KHANA has recognised the value of directly delivering HIV prevention interventions via its care services in a programme that puts the theory of “linking care and prevention” into practice.
Strategy 12:
Reinforcing positive prevention through harm reduction and needle exchange programmes

In countries where the epidemic has been concentrated among injecting drug users, different or additional HIV prevention strategies are required. Successful prevention programmes for injecting drug users employ a harm reduction approach and often feature needle exchange and drug substitution programmes, for example methadone services. Information and education about sexual transmission of HIV and condom provision is also included as part of prevention activities for drug users.

Many HIV positive people who use drugs find it more difficult to disclose their HIV status to sexual partners than to injecting partners. There is a clear need to reinforce positive prevention through existing harm reduction and needle exchange programmes to ensure that HIV positive people who use drugs receive the support they need to deal with issues around sexual health and relationships, disclosure with casual and long-term sexual partners and sexual issues associated with long-term drug use.

There are many examples of support groups for injecting drug users, such as Club Eney in Kiev, Ukraine.

Case study:
Establishing trust for HIV prevention, care and quality of life for injecting drug users in Kiev, Ukraine

Club Eney began as Ukraine’s first Narcotics Anonymous group. It was founded in Kiev in 1993. Since then, it has developed a wide range of support and assistance services for injecting drug users, many of whom are people living with HIV and some of whom sell, buy or trade sex.

The organisation, which has 33 workers, is operated entirely by drug users, some of whom still use drugs and some who do not.

Club Eney’s activities and services include:

- a mobile service that provides condoms, clean needles and syringes, and information on hygiene and safety to injecting drug users. Tea, coffee and psychological support are also available to those who use the service
- training
- a dating agency that helps HIV positive people to find friends and partners, and that organises special events for single HIV positive people
- counselling
- advocacy and support for drug users and people living with HIV
- ongoing services available in various places known as “trust points”. At the trust points the club organises regular meetings to support drug users. One trust point is at the hospital, operating in collaboration with the City AIDS centre. It offers voluntary HIV testing and counselling services, ARV treatment, and it recently started a substitution therapy programme
- a hotline that offers assistance to drug users
- support for drug users who want to re-enter the workforce, through a partnership with the City Employment Centre.

“It’s really great that Club Eney has organised trust points for drug users in Kiev. We can get counselling there, assistance, information on HIV, condoms and other help at a place and time that suits us. It’s really important because most of us are not well-off. Club Eney’s work among drug users is really saving our lives.” – Male drug user
Issues to consider

- HIV positive injecting drug users are regularly denied access to health care services, including ARV treatment, because of their drug use. More efforts are needed to develop different service models and to provide adequate training to health care providers to respond to the specific needs of injecting drug users, without discrimination. Mobile clinics, outreach services and services that address the other needs of drug users – these are some examples of the ways in which services need to adapt to meet the needs of drug users who are often highly stigmatised, very poor and who have many health and social support needs.

- It is important to combine improving services for drug users with advocacy efforts to ensure equal access to health care services, including ARV treatment, to all HIV positive people, including those who inject drugs.

- Understanding the particular needs of women who use drugs is an important dimension of positive prevention for drug users. Dependency on drugs can create particular pressures for women, and many need direct support from peers or from services to gain some control over both their injecting and their sexual lives. It is important to have separate support groups for women, and separate information and education on sex and sexual health, relationships, drugs and substitution therapy, and pregnancy and family planning services.
Strategy 13: Involving HIV positive people

The involvement of people living with HIV at different levels of programme implementation is a principle as well as a strategy, and is applicable across the entire framework of interventions. There are different levels of involvement, and individual HIV positive people should be encouraged to consider the level that suits them.

The Alliance/Horizons study on the greater involvement of people living with HIV/AIDS in NGO service delivery (2002) identified a gradient of ways in which people living with HIV can become involved in various aspects of prevention and care programming:

- The first step can be when HIV positive people access NGO services, such as medical care, counselling or training as beneficiaries or users.
- Accessing services may motivate some people living with HIV to become involved and gain experience in NGOs as support staff or volunteers in non HIV-related activities, such as driving or working as receptionists, or as occasional volunteers in HIV service delivery, such as outreach work, peer support and so on.
- This can lead to the delivery of HIV-related services on a formal, regular basis as employees or volunteers, using their experience of living with HIV, as well as skills and knowledge gained in formal training.
- Depending on their experience, training and skills, some may go on to take part in the design, planning and management of programmes and in organisational strategic planning.

Increasingly, people living with HIV are employed by NGOs as staff members and in governance. Capacity building for people living with HIV is important to ensure meaningful involvement in decision making and policy. It can include:

- personal empowerment
- communication and presentation skills
- HIV and AIDS technical knowledge
- organisational development skills
- legal aspects of HIV and AIDS
- representational skills
- leadership skills
- policy analysis
- documenting and reporting skills.

Issues to consider

- HIV prevention efforts targeting people living with HIV and other vulnerable populations are more effective when the target communities are involved. This involvement can also contribute towards reducing stigma in their community. The involvement of people living with HIV in the planning, development, delivery and evaluation of positive prevention enhances the relevance and reach of these interventions.
- HIV positive people have the right to make decisions about the level and type of their involvement. They also have the right to choose to be involved without making their HIV status public.
- Organisations need to create an organisational culture that is conducive to meaningful involvement. This includes promoting behaviours, language and attitudes that encourage involvement. As well as organisational policy that supports people with HIV to work effectively at all levels of an organisation.
Strategy 14: Advocacy for HIV prevention

As the global commitments towards universal access to HIV prevention, treatment, care and support by 2010 are implemented at a country level, the need for community-level advocacy to achieve these targets is increasingly important. HIV prevention programmes are best delivered as part of a continuum of interventions and services that include treatment, care and support interventions and services. Advocacy efforts must attend to the access barriers across the spectrum of services to ensure that universal access is delivered in HIV prevention, treatment, care and support not just in one or two of these areas. In addition, advocacy for an enabling environment for HIV prevention, including positive prevention, is vitally important to address HIV-related stigma and discrimination, and discrimination on the basis of sexuality, sex work or drug use.

Advocacy initiatives for positive prevention should include:

- supporting leadership from within HIV positive communities
- ensuring a sustainable supply of condoms and lubricants that meet the real demands of the population. People living with HIV need to access free condoms and lubricants from health care facilities, home-based care services and community groups to ensure they have the means to maintain safer sex practices
- ensuring access to clean injecting equipment and to drug substitution programmes for people who inject drugs
- recognising the particular needs of marginalised groups, such as HIV positive people in prisons, mobile and displaced HIV positive people and asylum seekers, and their need to access prevention services
- increasing prevention options for HIV positive women, including advocacy for the development of new technologies such as microbicides and increasing availability of female condoms
- financing for comprehensive HIV prevention, treatment, care and support services.

Issues to consider

- Advocacy efforts are stronger when they include people living with HIV. Mobilising the voices of people with HIV who need services has a powerful effect on decision-makers.
- Where ARV treatment is limited, it is important to recognise that an overemphasis on HIV prevention for people with HIV can have a stigmatising effect and can reinforce harmful stereotypes of HIV positive people as exclusively responsible for HIV transmission.

Advocating legal rights in India. Participants at a Lodi meeting hear about the legal rights of people living with HIV.

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Strategy 15: Creating a supportive legal and policy environment for positive prevention

Creating a supportive environment for positive prevention means acting to support the human rights of people living with HIV, including interventions to address HIV-related stigma and discrimination. HIV positive people need open and tolerant societies that provide the optimal conditions for disclosure and for promoting health and sexual and reproductive rights. Laws and government policy can have a powerful effect on these conditions. For positive prevention to work optimally, laws and policies should give HIV positive people real rights and protection from discrimination.

Anti-discrimination laws support positive prevention by creating a supportive culture in which HIV positive people can be open about their HIV status without fear of losing jobs and homes, being denied access to services – including health services – being excluded from school or denied other basic rights. By contrast, laws that criminalise HIV transmission undermine a culture of openness and support for people living with HIV, and therefore undermine positive prevention.

Sexual activity and drug use are complex human behaviours not easily prescribed or dealt with by laws, imprisonment or fines. Other approaches to HIV prevention, where people are supported and resourced to act responsibly, are more likely to be successful. Criminalising people for transmitting HIV creates an environment of fear, where HIV positive people are less likely to disclose their HIV status, and others are less likely to test. It also places the main responsibility for preventing HIV transmission on the person living with HIV, without acknowledging that there is a shared responsibility to promote health and prevent HIV transmission.

Public health laws offer practical alternatives to criminal laws in this area. Rather than criminalising and punishing, public health laws can support individuals to avoid practices that risk HIV transmission by addressing the underlying causes of unsafe sexual practice. In extreme cases, public health laws can provide coercive interventions for people who pose a high HIV transmission risk by using public health powers to detain individuals who persist in behaviour that puts others at risk.

Issues to consider

- Legal remedies and law reform to protect the rights of HIV positive people can have a powerful impact by enshrining their rights in law. But these processes – advocating and campaigning for law reform – can be lengthy and resource intensive. Coalitions of groups with similar interests have been effective in campaigning for HIV-related law reform.

- Supportive legal and policy environments are created not only by good laws and policy but also by good education – of the general public, of professionals and of specific communities. Education about HIV and AIDS in and of itself is not enough. The general public, professionals and specific communities need education about HIV-related discrimination and the harm it causes.
The right to health

The International Covenant on Economic, Social and Cultural Rights (1966) asserts that all people have the right to the highest attainable standard of physical and mental health. 148 countries have signed up to this covenant, which regards health as a right not a privilege. The Covenant holds that signatories must take steps to achieve the full realisation of this right, including prevention, treatment and control of epidemic, endemic, occupational and other diseases (ICESCR, article 12).

The Committee on Economic, Social and Cultural Rights, which monitors the Covenant, interprets the right to health as including those factors that often determine health or illness, such as access to safe food and water, nutrition, housing and health-related education and information, including education and information on sexual and reproductive health.

HIV positive people are centrally located in this Covenant, and under it have the right to health. Anti-discrimination programmes advocate for people’s right to access HIV treatment and also their right to education and information on sexual and reproductive health, including information about HIV transmission. Where HIV positive people are denied this information, not only do HIV treatment and prevention services fail but peoples’ fundamental rights are breached.
Eric Nachibanga is a support worker with ACER, a local NGO in Zambia, and national activist. He has known he is HIV+ since 1992. Among other activities, he holds peer education and counselling sessions in several bars and pool halls in Lusaka.

"I am very proud to be part of the group that successfully lobbied for free ARVs. But, we will continue facing more infections. If we can accelerate our efforts then things might slow down by 2010 or 2011. If not, then it will really be something else. Something not good.

Also, our efforts have been concentrated in the urban areas while there are people who are sick and isolated in rural areas with only very scanty provisions. To them HIV is like a myth, just bible stories. But, I also see signs of hope. I now hear Catholic priests are being flexible, saying a person can make a choice. I want to improve knowledge and provisions in the rural areas. I want to do it, but I can’t do it single handedly, but if I saw someone else who wanted to, I wouldn’t wait to put on my shoes to join this group.

Seeing how people are really suffering with the pandemic drives me. I am just a small fish, but I need to do more. I would love to see a cure. That would be worth every drop I have sweated for help with treatment."

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