Positive Prevention

Prevention Strategies for People with HIV/AIDS
Draft Background Paper

The International HIV/AIDS Alliance (the Alliance) is an international non-governmental organisation (NGO) that supports communities in developing countries to make a significant contribution to HIV prevention, AIDS care and to the provision of support to children affected by the epidemic. Since its establishment in 1993, the Alliance has provided financial and technical support to NGOs and community-based organisations (CBOs) from more than 40 countries.

The Alliance Emerging Practice Series consists of reports and papers which are currently in draft form, which we feel may contain useful information for people working on HIV/AIDS policy and programming, and people providing support to NGOs and CBOs in developing countries. The series is intended to provide updates on issues in areas where practice is being developed, and where debate and learning about good practice is still largely emerging.

This series of draft reports and papers is available in electronic form for people to download and print if they wish. The text of these reports and papers will be subject to change as additional information becomes available, and we would appreciate your feedback.

Once good practice begins to be agreed and consolidated, our intention is to use these drafts to form the basis of practical tools and technical support resources for use by NGOs and CBOs working on HIV/AIDS in developing countries, and for use by people who provide support to these organisations.

International HIV/AIDS Alliance

LIST OF ACRONYMS

ART	Antiretroviral treatment
CBO	Community-based organisation
CDC	Centers for Disease Control and Prevention (USA)
SW	Sex worker
GIPA	Greater involvement of people living with or affected by AIDS
IDU	Injecting drug user
MSM	Men who have sex with men
MTCT	Mother-to-child transmission
NGO	Non-governmental organisation
PCM	Prevention case management
PMTCT	Preventing mother-to-child transmission
PN	Partner notification
RRC	Risk reduction counselling
SAFE	Sero-status Approach to Fighting the HIV Epidemic
STI	Sexually transmitted infection
VCT	Voluntary counselling and testing

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International HIV/AIDS **Alliance**

> Risky behaviour by positive people is not the norm. Most of us take extraordinary steps to make sure that we are not infecting our partners, and we're doing so without a whole lot of support. There aren't massive public health interventions out there. There aren't big campaigns supporting us staying safe in our relationships. We're doing it of our own accord.

Terje Anderson, Deputy Executive Director, National Association of People with AIDS, USA
(cited in Collins et al. 2000)

This section looks at what we mean by positive prevention, why this background paper was researched, what is included in the text and what the limitations of the paper are. It also includes a list of important concepts used in positive prevention.

1.1 WHY POSITIVE PREVENTION

Effective HIV prevention programming will typically include a combination of the following:

- behaviour change programmes
- control of sexually transmitted infections (STIs)
- voluntary counselling and HIV testing (VCT)
- harm reduction programmes for injecting drug users (IDUs)
- interventions for prevention of mother-to-child transmission (PMTCT)
- blood safety measures
- infection control in healthcare settings
- structural interventions to alter the environment in ways that promote risk reduction.

More than 40 million people worldwide are now living with HIV. A weakness in prevention strategies in many countries has been the failure to target intensive prevention efforts to people who have been diagnosed with HIV. A comprehensive prevention strategy must therefore include programmes to assist people with HIV to take measures to avoid the possibility of exposing others to infection (Global HIV Prevention Working Group 2003).

People with HIV have always had an essential role to play in preventing new infections. HIV/STI prevention strategies have, however, often failed to address the distinct prevention needs of people with HIV and to acknowledge their significant efforts to avoid infecting others (Collins et al, 2000). There is an urgent need to sharpen the focus on prevention among people living with HIV (Global HIV Prevention Working Group 2003).

The advent of new treatments for HIV infection heightens this need for positive prevention, with more people living with HIV than ever before. The challenge is to implement this within an ethical framework – without putting people with HIV at increased risk of stigma and discrimination and without eroding their human rights.

> Strategies for positive prevention should aim to support people with HIV to protect their sexual health, to avoid new STIs, to delay HIV/AIDS disease progression and to avoid passing their infection on to others. Strategies for positive prevention are not stand alone, but work in combination with one another.

1.2 ABOUT THIS PAPER

This draft background paper has been developed as a resource by the Alliance for Alliance partners, NGO Support Programmes, networks of positive people and other interested individuals and organisations working in developing countries.

It aims to assist the development of focused HIV/STI prevention interventions for people with HIV by laying out in broad terms the rationale, context and options for prevention strategies for/by/with people with HIV.

The reader should note that this document is not a technical manual or 'how to' guide for practitioners. Rather, it is a starting point from which to think through programmatic issues and to contribute to a shared understanding of the basic issues.

This paper is still in draft in the anticipation that it will be updated as we learn more about positive prevention from the experiences of Alliance partners and others in developing countries.

This paper concentrates mainly on strategies that prevent onward transmission from people living with HIV through sex. It also includes interventions to prevent mother-to-child transmission (MTCT).[1] The focus of the paper is on strategies that are specific to people with HIV, so mainstream prevention strategies, such as condom promotion or STI diagnosis and treatment (which are also very important for prevention of onward transmission), are not included here. The paper also does not include prevention through blood transfusions, injecting drug use, and other exposure to bodily fluids by caregivers or healthworkers.

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[1] The term 'mother-to-child transmission' is used throughout the document for ease of use. However, the role and responsibilties of the father are also recognised.

1.2 About this paper

Knowing one's HIV status is important for prevention strategies with people with HIV, yet 90% of people living with HIV in developing countries do not know their status and have no means of finding out (Kitahata et al. 2002). This paper therefore covers a continuum of strategies, from helping people find out their HIV sero-status by increasing access to VCT, to enabling people who know they have HIV to reduce their risk of onward HIV transmission.

Section 2 shows why it makes good sense to implement HIV/STI prevention strategies with people with HIV. It outlines guidelines for good practice and dispels some common myths that exist around working with people with HIV. The epidemiological and human rights perspectives are both reflected in this section, including issues where the public health objectives are not always consistent with promoting and protecting the human rights of people living with HIV.

Section 3 introduces strategies for positive prevention grouped under four headings:

- Individually focused health promotion
- Scaling-up, targeting and improving service and commodity delivery
- Community mobilisation
- Advocacy, policy change and community awareness.

In this section, each strategy is briefly described. Examples are given and the evidence for the effectiveness of each strategy in positive prevention is reviewed. A list of issues to consider when adapting each strategy is also included.

Section 4 provides a list of references, follow-up reading and useful websites where further information can be obtained.

1.3 IMPORTANT CONCEPTS IN POSITIVE PREVENTION

A list of important concepts used in positive prevention is included here for reference:

Disclosure is the act of informing any individual or organisation of the sero-status of a person with HIV. However, the objectives and the consequences of disclosure may be beneficial or harmful.

Informed consent is based on the principle that competent individuals are entitled to make informed decisions regarding their participation in or agreement to HIV tests, other HIV/AIDS-related interventions, and to health providers disclosing their HIV status to others.

Partner notification (PN) Also known as contact tracing or partner counselling, is the process of contacting sexual or injecting partners of a person with HIV in order to advise them of their potential exposure to HIV and to encourage them to come forward for counselling, testing and – where applicable – treatment.

People living with HIV People infected with the HIV virus and/or experiencing AIDS-related illnesses or infections. Also defined as HIV positive or sero-positive.

Primary prevention Activities with both infected and uninfected people to reduce primary (ie. initial or new) HIV infections (Summerside and Davis 2002)

Secondary prevention Activities to maintain well-being of people with HIV (including wider sexual health), and delay disease progression (Summerside and Davis 2002)

Sero-discordant Where one partner is HIV positive and the other is HIV negative

Sex-positive A sex-positive approach supports people with HIV in enjoying a healthy sex life, and even encouraging them to do so (Summerside and Davis 2001).

Stigma Attitudes or perceptions of shame, disgrace, blame or dishonour associated with HIV/AIDS (De Cock et al. 2002). Stigmatisation is a social process not just an individual attitude (Parker and Aggleton 2002). Several authors also divide stigma into felt or perceived stigma and enacted stigma. Felt stigma refers to real or imagined fear of societal attitudes and potential discrimination related to having HIV, or association with a particular group. This means, for instance, that sex workers (SWs) with HIV can face 'double stigma'. Enacted stigma refers to the real experience of discrimination (Brown et al. 2001).

Viral load The amount of HIV in an HIV infected person's body. Viral load levels are used as an indicator of how well a person with HIV's immune system is dealing with HIV (Terrence Higgins Trust Briefing Sheet on Viral Load and Infectiousness, Sept. 2002).

Vulnerability refers to enhanced susceptibility to HIV infection or its consequences. The concept of vulnerability recognises the restricted behavioural choices that exist for many people, and the different levels of risk for HIV infection that the same behaviours might carry in different epidemiological, socio-economic, cultural and policy contexts (De Cock et al. 2002).

1.4 LIMITATIONS OF THIS PAPER

Prevention strategies for/by/with people with HIV are limited in this background paper to those that have been evaluated and documented in the published literature or in reports accessible from web-sites. There are many gaps in this evidence base, and many of the strategies documented have not yet been implemented and evaluated in low HIV prevalence, developing countries, nor with diverse vulnerable groups.

It is also clear that work on positive prevention is being carried out in developing countries but that this work has not yet reached the mainstream literature. There is a need to supplement this information with case studies from programmes that are as yet undocumented and to follow the practice of positive prevention as it evolves.

As far as the published literature is concerned, a number of things became clear during the review:

- Positive prevention has only recently emerged as an area of interest, particularly in the USA with Centers for Disease Control and Prevention's (CDC) launch of the Sero-status Approach to Fighting the HIV Epidemic (SAFE).

- Most of the available studies are limited to descriptive studies, or use simple correlation for statistical analysis. Only a few experimental and longitudinal studies exist to assess the impact of interventions on well-being, behaviour or disease outcomes.

- A large proportion of the literature focuses on gay men in Europe, Australia and the USA. This limits the extent to which findings can be applied to other population groups and to cross-cultural contexts where different factors influence sexual attitudes and behaviours.

- Other relevant studies have been carried out in developing country contexts with heterosexual population groups. Many of these have been in high HIV-prevalence contexts and their effectiveness in other, lower prevalence contexts is not yet known. The maturity of the epidemic does, for example, influence the effectiveness of uptake and return rates for VCT. Where the epidemic is less well-established, ignorance, denial and stigma may be more closely associated with HIV testing than in other places.

- The perspectives of people with HIV have often been obscured by research on sexual behaviour that has implicitly assumed that all respondents are HIV negative.

- People with HIV have had limited involvement in interpreting research findings, which can mean that findings often reflect external assumptions rather than the lived experience of people with HIV.

- Most of the research focuses on unprotected sex *per se*, regardless of the HIV sero-status of the sexual partners involved. Yet it is sero-discordance that is an essential precursor to onward HIV transmission (Summerside 2001; Summerside and Davis 2002; UNAIDS 2001).

- Finally, prevention strategies shown to be effective in the published literature are still not widely accessible. There is a massive scaling up of prevention services still to be carried out. Only 12% of people who want to be tested for HIV are able to access VCT services globally and only 6% have access in sub-Saharan Africa (Global HIV Prevention Working Group 2003).

2.1 Why Positive Prevention strategies are needed

This section explains why positive prevention is necessary and attempts to give some guidance around good practice in positive prevention.

2.1 WHY POSITIVE PREVENTION STRATEGIES ARE NEEDED

Most prevention strategies to date have been targeted at uninfected people to prevent them from becoming infected with HIV. Historically, there has been a reluctance to work on HIV/STI prevention with people with HIV because of perceptions that the concept of prevention for people already infected is inherently contradictory. There have also been justifiable concerns about victimising an already stigmatised group. In addition, there has been a reluctance to acknowledge that people with HIV have sex, and also to get to grips with the complex ethical issues surrounding people with HIV's responsibilities towards others (Collins et al. 2000; De Cock et al. 2002; King-Spooner 1999; Remien et al. 2000; Summerside and Davis 2002).

On the other hand, there are very compelling reasons for considering prevention activities that meet the particular needs of people with HIV. Firstly because one positive person is involved in each case of HIV transmission; secondly, because people with HIV have the right to live well with HIV; and thirdly, because HIV prevention, treatment, care and support are all inter-related. To explain further:

1. One positive person is involved in each case of HIV transmission
From an epidemiological and public health perspective, the most important group to address with HIV/STI prevention strategies are people already living with HIV. This is particularly the case in low prevalence settings where the epidemic is contained in certain core populations (Collins et al. 2000).

Preventive interventions with positive individuals are likely to have a greater impact on the epidemic, for an equivalent input of cost, time, resources, than preventive interventions focused on negative individuals. A change in the risky behaviour of an HIV positive person will, on average and in almost all affected populations, have a much bigger effect on the spread of the virus that an equivalent change in the behaviour of a negative person *(King-Spooner 1999; Vernazza et al. 1999).*

2.1 Why Positive Prevention strategies are needed

Sero-discordant couples are a particularly important group to support, as are infected pregnant women who are at risk of transmitting HIV to their infants (de Cock 2002). Epidemiological models suggest that working particularly with people who have been infected very recently will have maximum impact on the spread of HIV (Cates et al. 1997).

2. People living with HIV have the right to live well with HIV
From a human rights perspective, people with HIV have a right to know their HIV sero-status. They also have the right not to know (Temmerman et al. 1995). Whether aware of their status or not, a person living with HIV has the right to live well with HIV, which includes having a healthy sex life. This requires strategies that support people with HIV to protect their sexual health, to avoid new STIs and to delay HIV/AIDS disease progression.

Having an STI can increase the risk of passing HIV onto a partner through sex. There is also a growing body of evidence that prevention strategies are required to protect people with HIV from HIV re-infection or superinfection; that is, becoming infected a second time with another 'strain' of HIV, including drug-resistant strains (Terrence Higgins Trust 2001).

Studies indicate that people with HIV have specific prevention requirements that demand tailored communications or service delivery strategies (Collins et al. 2000). For instance, women living with HIV have the right to information to support their choices for pregnancy planning. The challenge is how to meet these specific needs without increasing stigma.

3. HIV prevention, treatment, care and support are inter-related
The prevention-treatment-care continuum reinforces the rationale for supporting prevention interventions for people with HIV. For example, people living with HIV need access to medical care and psycho-social support services, and also support to build their skills for adopting and maintaining safe behaviour. HIV prevention programmes have been successfully linked with HIV care in Thailand, Cambodia, Uganda and Senegal, while Brazil is regarded as a leading example of the integration of HIV care and a renewed commitment to prevention (Kitahata 2002).

> " Programmes would not be complete without the combination of prevention and care. It's not meaningful if you do prevention without care, or care without prevention. The elements are inter-related and can't be separated. They're both integral to an effective programme.
>
> *Clement Mufuzi, Network of Zambian People Living with HIV/AIDS*
> *Cited in Care, Involvement and Action: Mobilising and support community responses to HIV/AIDS care and support in developing countries, International HIV/AIDS Alliance, July 2000, p. 7.* "

> 🔍 **Examples of this continuum include:**
> The promotion of VCT for behavioural change allows those with positive test results to be referred to care and support services or to services that will reduce the chance of MTCT. Access to care and treatment programmes in turn provides additional opportunities to promote condoms and information on how to live safely with HIV (International HIV/AIDS Alliance 2002). Belonging to a post-test support group helps people cope with issues such as disclosure, safe sex or safe injecting strategies.

2.2 GUIDING PRINCIPLES FOR GOOD PRACTICE IN POSITIVE PREVENTION

People with HIV face many constraints to changing their behaviour and reducing the risk of onward transmission. As mentioned above, most do not even know their HIV sero-status. Even if they are willing and able to find out their status, they may well not have the knowledge or the ability to reduce the risks of onward transmission.

Disclosure of one's sero-status is difficult for many people with HIV, especially women, who may fear stigma, rejection or violence from their partners, and discrimination in the wider community or by healthproviders.

Practicing safer sex with all partners and always using clean needles are key prevention strategies. Many people with HIV, however, are not able to obtain condoms or clean needles. Even if they can access these basic commodities, they may not be able to negotiate their use for a whole variety of cultural, social and personal reasons. Understanding the concept of vulnerability is therefore just as important in developing prevention strategies for people living with HIV as it is for all prevention strategies.

The design of an intervention must be informed by the economic, social and cultural determinants of vulnerability. Interventions must work not only with the person living with HIV, but also with those who influence or restrict their behaviour and options. Additionally, efforts to create enabling environments for prevention with people with HIV are needed to address structural barriers faced by people with HIV, such as poverty and restrictive laws and policies.

Before reviewing the available evidence on prevention interventions for people with HIV, it is therefore helpful to keep in mind a set of principles

to guide the design and implementation of effective strategies. The suggested principles will need to be refined and added to, particularly from the perspective of men and women living with HIV:

- Effective prevention is based on a marriage between what is known to be effective (the evidence base) and the meaningful participation of people with HIV in how best to apply this evidence base to their local context. This means it is important to actively involve people with HIV and affected communities in identifying risks and in assessing how best to implement strategies for positive prevention in their situation. In 2003 the Alliance and partners carried out Participatory Site Assessments in 39 sites in three countries with the active involvement of people with HIV.

- Combine strategies to create enabling environments which facilitate the empowerment of people with HIV. Recognise that the behaviour of people with HIV is influenced by the context in which they live their lives and that there will be factors that enable or hinder behaviour change in every situation.

- Protect and promote human rights and ethical principles, including the right to privacy, confidentiality, informed consent, freedom from discrimination, and the duty to do no harm. Strategies and policies that erode human rights and ethics and create an environment of fear, intolerance and coercion will undermine positive prevention interventions. Protecting human rights in positive prevention means encouraging voluntary testing, beneficial disclosure, ethical partner counselling and appropriate use of HIV case surveillance.

- Implement strategies in a way that keeps stigma and discrimination against people with HIV to a minimum, whilst still focusing on the particular needs and rights of people with HIV.

- Be gender sensitive so that interventions address the gender relations and power dynamics between women and men, and recognise that these influence the effectiveness of positive prevention strategies. Gender dynamics often become even more critical when one or both partners are living with HIV. For example, women who already have little decision-making authority in a relationship may face additional burdens of social exclusion, abandonment and violence if they disclose their positive HIV status (Garcia-Moreno et al. 2000).

- Balance the public health objective for HIV/STI prevention with the sexual well-being needs and rights of people with HIV. An over-emphasis on people with HIV's individual responsibility or 'moral duty' to change their behaviour is not always effective in promoting sexual or injecting safety. Interventions need to understand and respond to the sexual and emotional needs and desires that motivate people and adopt 'sex-positive' approaches (Summerside and Davis 2002).

- Confidentiality and informed consent are not only valid ethical principles, but also effective public health tools by which to protect both people with HIV and those not infected. The following text shows where there is a tension between ethical principles and people's perceptions of what is effective in positive prevention. Although the cases are not clear cut, most of the evidence shows that following ethical principles makes for effective prevention with people with HIV. It is acknowledged that some of these issues are extremely complex and have been simplified here for the sake of brevity.

It has been said that: *'A person with HIV who has unprotected sex is irresponsible or deliberately trying to infect someone'*

This assumption is erroneous in the vast majority of cases and can lead to increased stigma and blame. In most countries, if a person is infected by someone with HIV who has been made aware of their HIV status and who also understands how the infection is transmitted, then the new person infected does indeed have a right to consider they have been the victim of an assault and to justice through the legal system. Most people who know they have HIV and understand how HIV is transmitted, however, go to extraordinary lengths to make sure that they protect their sexual partners. Often there are enormous barriers to this in terms of possible stigma and rejection, and in the case of women, the risk of violence and abuse. This leads to a great deal of fear and guilt, and people with HIV need support to address these barriers. Without proper support, people who think they have HIV may even be reluctant to come forward for VCT or positive prevention services.

It has been said that: *'Confidentiality and informed consent are obstacles to effective prevention and care efforts'*

Some organisations are concerned that the principles of confidentiality and informed consent allow people with HIV to refuse to share their sero-status with sexual or injecting partners or the wider community. This can then hinder efforts to prevent the spread of HIV and deny protection to the partners of those people with HIV (De Cock et al. 2002). Some people

2.2 Guiding principles for good practice in Positive Prevention

think that confidentiality also contributes to the general denial of HIV/AIDS within communities and by leaders. These concerns have led to calls for the following three policies and strategies. However, experience shows that not only are the human rights of people with HIV compromised by these strategies, but the public health goal of HIV/STI prevention is often not achieved either.

It has been said that: *'Mandatory (compulsory) disclosure and partner notification helps prevent further cases of HIV'*
Mandatory disclosure and PN actually does little to contribute to HIV prevention. There is no clear data indicating that mandatory notification of partners is more effective in preventing HIV transmission than the voluntary notification/counselling of partners. Mandatory PN is likely to deter people from using HIV testing and counselling services because of the serious stigma and discrimination surrounding HIVAIDS, thereby hindering prevention efforts. Furthermore, large-scale PN is not feasible in practice: it is virtually impossible to force people to test or re-test for HIV, and people do not always know or remember the names of their sexual partners (UNAIDS/WHO 2000).

It has been said that: *'Criminalising people with HIV who knowingly expose or transmit HIV will reduce HIV incidence'*
This is not an effective prevention strategy. In fact, these coercive powers may cause a loss of trust and confidence by vulnerable populations and discourage people with HIV from learning their HIV status voluntarily, thereby undermining prevention efforts. Further, these types of laws increase discrimination by suggesting that people with HIV are more irresponsible than others (King-Spooner 1999; Speissegger et al. 2001).

It has been said that: *'Name-based HIV case reporting helps with prevention efforts'*
Named case reporting can become a barrier to prevention efforts for people with HIV. Named case reporting to public health authorities should be used as a means to link individual people with HIV to HIV care, risk reduction counselling and PN, and to provide information on the spread of HIV. However some studies (particularly among men who have sex with men (MSM) in the USA) have indicated that people are less likely to come forward for VCT under a name-reporting system. Moreover, in resource-poor settings, where the reporting infrastructure cannot guarantee confidentiality, it is recommended that HIV case reporting not be carried out. Investing in VCT is more cost-effective (Shriver et al. 2000; UNAIDS/WHO 2000).

Seventeen positive prevention strategies are discussed in this section in four categories. The categories are taken from the Alliance *Frontiers Prevention Project Framework* (International HIV/AIDS Alliance, Oct. 2002).

The table below outlines each strategy in the four categories. The rest of the section gives the following information for each strategy:

- Name of strategy
- Aim of strategy
- Description of strategy with examples of activities
- Evidence for the effectiveness of the strategy in positive prevention
- Issues to consider when adapting the strategy.

When using this section and table, it should be noted that most of these interventions are not stand-alone, mutually exclusive strategies. Rather, organisations will need to implement a combination of these strategies alongside each other – perhaps in partnership with other organisations (Global HIV Prevention Working Group 2003). The combination of strategies implemented will depend on the specific needs of the people with HIV, the local social and institutional context, resource availability and the capacity of the implementing organisation(s).

3.1 Individually focused health promotion	3.2 Scaling up, targeting and improving service and commodity delivery	3.3 Community mobilisation	3.4 Advocacy, policy change and community awareness
Strategy 1: Promoting voluntary counselling and testing	*Strategy 5: Ensuring availability of voluntary counselling and testing*	*Strategy 9: Facilitating post-test clubs and other peer support groups*	*Strategy 14: Involving people with HIV in decision-making for Positive Prevention*
Strategy 2: Providing post-test and ongoing counselling for positive people	*Strategy 6: Providing antiretroviral treatment for Positive Prevention*	*Strategy 10: Implementing focused communication campaigns*	*Strategy 15: Advocacy for Positive Prevention*
Strategy 3: Encouraging beneficial disclosure and ethical partner notification	*Strategy 7: Reducing stigma and integrating Positive Prevention into treatment centres*	*Strategy 11: Training people with HIV as peer outreach workers*	*Strategy 16: Legal reviews and legislative reform*
Strategy 4: Providing counselling for sero-discordant couples	*Strategy 8: Providing services for preventing mother-to-child transmission*	*Strategy 12: Reinforcing Positive Prevention through home-based care*	*Strategy 17: Advocacy for access to treatment*
		Strategy 13: Addressing HIV-related gender-based violence in Positive Prevention	

3.1 INDIVIDUALLY FOCUSED HEALTH PROMOTION

At the individual or couple level, interventions for people with HIV can be summarised under the general heading of 'prevention counselling'. The main objectives of prevention counselling are to:

- strengthen awareness of HIV
- increase knowledge about HIV/STI risk reduction strategies
- strengthen the desire and motivation for HIV/STI prevention
- strengthen skills in risk reduction and communication
- increase the demand for services and commodities.

Counselling is important from the stage at which a person is unaware of their HIV sero-status. The following prevention strategies for people with HIV start with approaches that encourage people to learn their HIV status, and move on to enabling people with HIV to prevent onward transmission of HIV and to live positively with HIV.

Counselling for prevention can take many forms, as these strategies outline (see Chippindale et al. 2001). Yet most of these behavioural approaches are based on the assumption that people with HIV should take personal, practical and ethical responsibility to prevent passing on HIV to others. However, this assumption must be balanced by the need also for communities and society to take collective responsibility to create the conditions in which both people with HIV and sero-negative people can make healthy choices (Marks et al. 1999). For this reason, community mobilisation and advocacy/policy change strategies must be implemented in combination with these individually focused health promotion strategies.

STRATEGY 1: PROMOTING VOLUNTARY COUNSELLING AND TESTING

Objective of strategy 1:
To encourage demand for HIV testing through raising individual awareness of the benefits of knowing HIV status.

Description of strategy 1:
Mass promotion of VCT among populations with high risk behaviour in high-prevalence, geographically circumscribed areas is increasingly being implemented. These campaigns use marketing strategies and multiple forms of media to strengthen motivation for testing (Janssen et al. 2001). These media campaigns also target the stigma associated with testing and a diagnosis of HIV infection.

3.1 Individually focused health promotion

Strategy 1: Promoting voluntary counselling and testing

One example of mass promotion of VCT is the Know Now campaign implemented by CDC in the USA as part of SAFE *(Janssen et al. 2001; Valdiserri RO et al. 1999).*

CDC also implements National HIV Testing Day and Prevention for people with HIV campaigns using television, radio and internet media.

Social marketing of VCT is a variation of mass promotion, but with increased audience targeting and a focus on promoting a social product, such as the value of early diagnosis of HIV infection. Audience targeting is especially important when attempting to promote early diagnosis for people with HIV who are unaware of their status.

For example, the Zimbabwe National AIDS Commission launched the New Start programme with Population Services International (PSI) and USAID. New Start uses franchising to provide VCT services, and has created a national VCT network with a common logo and name, which is promoted through media and information campaigns. High-quality counselling and testing services are offered at the programme's centres, with same-day results at most of them. All sites use a standardised counselling and testing protocol, and free services are offered for clients unable to afford the standard fees *(UNAIDS 2002).*

Similarly, a pilot programme to accredit VCT services and help assure quality through adherence to national VCT guidelines, was found to be feasible in government, private and NGO sectors in Kenya *(Doyle et al. 2002).*

The social network/peer educator approach encourages people with HIV to provide information and outreach to peers who might be positive. This strategy creates a more efficient and targeted approach to HIV VCT for those at greatest risk (Remien et al. 2000). The use of targeted papers, flyers, posters, and educational videos in health centre waiting rooms can complement this approach, and tends to be less expensive than mass media campaigns.

3.1 Individually focused health promotion

Strategy 1: Promoting voluntary counselling and testing

For example, Child Survival India integrated a community-based intervention to promote VCT into their ongoing programmes in rural Delhi. They trained local community leaders and youth volunteers (including people with HIV) to act as peer outreach educators, providing HIV/STI prevention education and referral to VCT services *(Bajaj 2002).*

Evidence for the effectiveness of strategy 1 in positive prevention:
HIV prevention mass media campaigns have been shown to result in increased HIV testing in USA studies (see Valdiserri et al. 1999), but increases have often been among those who are not actually found to be HIV positive. This emphasises the need for preliminary research with people with HIV to ensure appropriate targeting of media, messages, timing of broadcasts, to promote VCT to undiagnosed vulnerable groups.

Campaigns led by NGOs in Thailand to encourage testing have created more openness and discussion about HIV. In the parts of the country where VCT has been made reasonably accessible to affected communities, the synergistic link between stigma reduction, increasing VCT and encouraging disclosure has been confirmed (UNAIDS/WHO 2000).

Whilst not based on a robust evaluation methodology, the Child Survival project in India found that peer educators were able to overcome socio-cultural barriers, were gender sensitive, were cost-effective and were able to integrate prevention of onward transmission with care and support (Bajaj 2002).

Issues for consideration when adapting strategy 1:
Promotion of VCT is first and foremost based on the intent that everyone who wishes to has a right to know the test result. It implies that the right to know is as fundamental as the right not to know, and that services are confidential. Studies in Zambia (Ffylkesnes 1999) and in Kenya (Temmerman et al. 1995) found that utilisation of VCT was low because people had concerns about confidentiality and length of waiting time for test results. Return rates for test results were also low for women, who feared domestic violence from a positive result. Special efforts must be made to ensure that HIV testing is not coercive, and that a community is ready to accept an increased number of people with HIV (Levi 2002; Mills 2002).

3.1 Individually focused health promotion

Strategy 1: Promoting voluntary counselling and testing

Promoting the importance of early detection of HIV infection (within the first six weeks) is needed, since infectiousness is greater in this primary phrase. Opportunities to link people with HIV with prevention services at this early stage must be taken (UNAIDS 1999).

Readiness for VCT in the general population can affect uptake of VCT. It is therefore very important to involve the community in the development of new services and to build the capacity of communities to provide ongoing support to VCT services. For example, Zimbabwe AIDS Prevention and Support Organisation used participatory reflection and action tools to develop a community action plan (Godfree et al. 2002).

There is a need to assess the local context to understand both the motivations for and barriers to coming forward for testing. This includes understanding the detrimental consequences of knowing one's HIV status: community-level stigma, individual-level violence or psychological abuse, relationship breakdown, possible abandonment by partners in the case of women (Garcia-Moreno et al. 2000, global review; Gielen et al. 2000; Kumaramanglam and Sabapathy 1996 in India; Meursing 1997 in Zimbabwe; Zierler et al. 1996; Zierler et al. 2000 in USA).

Great care must be taken not to actually create stigma through VCT by limiting activities to particular population groups or geographical areas. Interventions to reduce stigma and to diminish discrimination against people with HIV, including violence prevention, should be implemented at community, health system and legal levels, in parallel with increasing demand for VCT (Mills 2002).

VCT is often promoted as a tool to diagnose HIV, but promotional messages must also focus on its benefits for prevention.

Promoting VCT for behavioural change as a prevention strategy alone will work less well if care and support services or referrals are unavailable for those found to be positive. Conversely, using VCT to identify HIV-positive individuals without then trying to promote behaviour change for prevention does not make full use of the strategy (FHI Focus 2001).

In contrast to the problems of testing without offering access to care, there is the HIV exceptionalism issue to consider, which says that insistence on over-elaborate pre- and post-counselling is holding back wider implementation of much-needed HIV testing (De Cock 2003; recent *Lancet* series on HIV in Africa).

Strategy 2: Providing post-test and ongoing counselling for positive people

As the capacity of health systems and community networks to provide care to people with HIV/AIDS improves (especially PMTCT), the demand for VCT services, even in resource-poor settings, will increase.

Where people fear mandatory HIV testing, or disclosure involving lack of confidentiality, they are likely to avoid HIV counselling, testing, treatment and support because their HIV status may become known against their will, and lead to negative consequences.

STRATEGY 2: PROVIDING POST-TEST AND ONGOING COUNSELLING FOR POSITIVE PEOPLE

Objective of strategy 2:
To empower people with HIV to adopt and maintain safe behaviours and to live positively.

Description of strategy 2:
Individual risk assessment and risk reduction planning are integral components of pre- and post-test counselling and can be continued through ongoing individual or collective support. Good counselling, both before and after receiving an HIV test result, can be critical in determining how people then view and act on prevention. Peer counsellors can enhance the quality of this support.

Post-test counselling provides the first opportunity after diagnosis to discuss prevention strategies and to make referrals to prevention, treatment, care and support services.

Although a critical component of prevention, post-test counselling is often lacking or of poor quality. For example, the Asia Pacific Network of people with HIV (APN+) found that only 24.5% of respondents in Malaysia had received post-test counselling (Paxton et al. 1999, cited in the Alliance Nov. 2000). Similarly, a situation assessment of people with HIV in Ecuador found that most people with HIV did not receive pre-test counselling and few received post-test counselling (Ayarza and Reyes 2002).

Ongoing one-to-one counselling of people with HIV is a type of counselling that encompasses a number of formal and informal holistic behavioural approaches to helping people with HIV live well and reduce the risk of onward transmission.

Strategy 2: Providing post-test and ongoing counselling for positive people

Ongoing group counselling of people with HIV follows much the same principles but in addition facilitates mutual support within the group.

The essentials of these approaches are to be found in many settings under different names. Some examples which are well documented are given below.

Prevention case management (PCM) is a time-limited, client-centred behavioural intervention designed to assist people with HIV as well as HIV-negative people. It is derived from a mix of HIV risk reduction counselling and clinical case management, and provides intensive, one-to-one support and prevention counselling. There are seven essential components of PCM: client recruitment; assessment of the people with HIV and STI risk behaviour, and medial and psychosocial needs; risk reduction counselling; development of a client plan; provision of referrals to other services for both HIV and non-HIV related needs; follow-up monitoring; and discharge. The first case management appointment usually occurs a couple of months after HIV testing, and follow-up meetings are arranged according to need. PCM has been implemented by both CBOs and government health departments in the USA in a variety of settings, such as VCT sites, methadone maintenance clinics, STI clinics, or free-standing centres *(CDC 1997; Collins et al. 2000).*

Risk reduction counselling (RRC) tends to be group based rather than focused on an individual people with HIV. Effective RRC strategies address issues that people with HIV have identified as being relevant to their lives and impact upon their ability to engage in safer sexual or injecting behaviour. RRC sessions include: identifying triggers for unsafe sex; ways to incorporate new safe sex strategies; defining 'healthy sex'; disclosure of HIV status to sexual partners; increasing social skills; learning assertive communication skills *(Lemke and Barland 1999).* Peer-based RRC is increasingly popular, where trained people with HIV or 'buddies' facilitate group counselling sessions for other people with HIV. RRC can take place in a variety of settings and provides social networking opportunities as well as building risk reduction skills.

Strategy 2: Providing post-test and ongoing counselling for positive people

There are some documented examples of CBOs and AIDS service organisations in developing countries that are empowering people with HIV to facilitate group counselling workshops for people with HIV. For example, Kuala Lumpur AIDS Support Services Society *(Wong 2002)*; Vivo Positivo in Chile *(Guajardo et al. 2002)*; Ruben Perez Silva Services Centre for people with HIV in Mexico *(Pazarin-Osornio and Kendall 2002)*. However, it is not clear to what extent the focus will be on risk reduction for prevention, compared to care and support issues.

Another approach to groupwork from the United Kingdom is a community-based initiative called Living Well. It is designed to empower people with HIV to enhance their health and well-being by taking greater control of their lives and developing better self-management skills. It consists of a combination of facilitated group exercises and guest speakers providing information and advice designed to: empower people with HIV to build personal strategies to support their sexual health, general health and well-being; strengthen coordination and referral processes among service providers; develop social networks among people with HIV. The programme lasts for six sessions over six weeks, with a follow-up programme to put what is learnt into action *(Ojwang et al. 2002; THT 2002)*.

An updated version of Stepping Stones will be developed and produced in 2003/2004 and will include more about working with PLHA. It will be available through TALC.

People with HIV trained as counsellors can play a vital role by drawing upon their experience of living with HIV. It is important that these counsellors are well trained, supported and remunerated.

Strategy 2: Providing post-test and ongoing counselling for positive people

In the Ivory Coast, for example, people with HIV who have trained as counsellors work in HIV/AIDS care centres *(Gueu et al. 2000, cited in Alliance Nov. 2000).*

Evidence for the effectiveness of strategy 2 in positive prevention:
An evaluation of PCM programmes for people with HIV implemented between 1989 and 1992 in three community health centres in the USA found that significantly more of the clients who had a follow-up meeting with the prevention case manager after four to six months had reduced some of their risk behaviours compared to the first PCM meeting. However, no differences were found in the number of new sex partners or use of condoms with a regular sex partner. However, there were problems with the evaluation methodology such as: a failure to collect behavioural data in the time between HIV testing and the first PCM appointment; no data on the sero-status of sex partners and how this relates to reported condom use; small sample size (CDC 1997).

An assessment of a similar programme for African-American and Hispanic gay and bisexual men living with HIV in the USA found that following the intervention, significantly more clients used a condom each time they had sexual intercourse and more clients were sexually abstinent during the previous four months (Menzer et al. 1992).

More recently, a study in Virginia, USA, found marked behavioural changes in PCM clients, resulting in a four-fold decrease in STI incidence (Rollison 2002).

Experience suggests that key to the success of PCM is integrating prevention components with antiretroviral treatment (ART) and care. In this way, not only are the behavioural aspects of HIV addressed, but also the medical and support needs of people with HIV. Some studies indicate that PCM clients do not perceive a need for HIV prevention, but remain with the PCM programme because of the treatment and support benefits (CDC 1997).

In Brazil, integrated prevention, care and support services were found to be especially important for IDUs living with HIV who face dual exposure to HIV/STI, double stigma and heightened psychosocial and social needs. IDUs who were fully engaged in ART protocols reported reductions in injecting behaviours and frequent condom use (Malta et al. 2002).

Strategy 2: Providing post-test and ongoing counselling for positive people

An experimental study of group counselling for people with HIV at a HIV treatment clinic in the USA found no significant differences in risk practice between the intervention group and control group. This study suggests that group work in a clinical context may not be an acceptable setting for people with HIV (Summerside and Davis 2002).

Talking to peers more generally (including in a support group situation) has been found to be critical for people with HIV to gain support after diagnosis. The experience offers encouragement and hope; some describe it as literally 'life-saving' (Katele 2000; Pawar 2000, cited in Alliance Nov. 2000).

A study in Nairobi, Kenya, found that HIV-positive counsellors had significantly more clients making return visits for support counselling after their initial test than counsellors who had not disclosed or did not know their sero-status. Through observation of the two groups of counsellors during supervision sessions, the known people with HIV counsellors were found to be very open, accepting and had a high level of self-awareness. The other group found it harder to empathise with clients appropriately (Mutsungah et al. 2002).

More rigorous research is needed to assess the impact of post-test counselling by people with HIV peers on the risk behaviours of people with HIV, particularly in low-prevalence settings.

Issues for consideration when adapting strategy 2:
One-to-one ongoing counselling of people with HIV is a resource-intensive strategy. It relies on a strong health system, good referral sources in the community, well-trained providers, and availability of other social, psychosocial and medical resources.

It is important to note that the PCM approach has not been used in settings where ART is not available. The potential synergies between PCM, treatment and care are likely to be reduced where ART is not available.

Counsellors need training in sexuality and culturally appropriate sex positive approaches, not just the basics of safer sex. The challenge is to empower people with HIV to shift to a new way of being sexual that is felt by the client to be satisfying. An overemphasis on condoms may lead to a feeling that safe sex is punitive. Learning different techniques for non-penetrative sex may help to overcome this.

Strategy 2: Providing post-test and ongoing counselling for positive people

Recruitment and retention of clients for ongoing counselling needs considerable efforts. Recruitment is particularly difficult for stand-alone programmes that do not have an internal source of referrals from other prevention, medical or social services.

Clinic-based settings are not suitable for group counselling. Evidence from industrialised countries suggest that the promotion of group work as social gatherings rather than 'safer sex workshops' is more attractive to some positive people.

People with HIV must be involved in the design, development and delivery of group work.

Sustaining behaviour change over the lifetime of the people with HIV is the big challenge – whatever the strategy.

Counsellors need adequate training, remuneration and strong support from colleagues, peers and other counsellors (Meursing 1997, cited in Alliance 2000). Inadequate preparation and training can leave counsellors feeling overwhelmed and frustrated.

Regular support supervision of counsellors is needed to ensure they are able to share issues in a confidential and supportive environment and benefit from the guidance of a senior counsellor supervisor (Mutsungah et al. 2002).

When we talk about 'peer' counsellors or outreach workers, the notion of peer needs extending beyond having HIV in common. SWs, MSMs and IDUs will relate much better to someone who has experience of their situation and who understands their lifestyle.

3.1 Individually focused health promotion

Strategy 3: Encouraging beneficial disclosure and ethical partner notification

Objective of strategy 3:
To share one's sero-status and to inform sexual/injecting partners of their potential exposure to HIV, in order to offer early HIV diagnosis, counselling, prevention and care.

Description of strategy 3:
Beneficial disclosure is voluntary and based on informed consent. It respects the dignity and autonomy of the affected individuals and maintains confidentiality as appropriate. Beneficial disclosure leads to beneficial results for the individual people with HIV and for their sexual and drug-injecting partners and family, and leads to greater openness in the community about HIV/AIDS. In addition, beneficial self-disclosure of an HIV positive status may also facilitate social support for people with HIV (Latkin et al. 2001) and can help with coping with HIV (Summerside and Davis 2002).

> Beneficial disclosure could be when a person with HIV chooses to inform a sexual partner of his/her status for prevention purposes, or informs family, community members or healthcare workers in order to obtain better support, care and prevention.

If not carried out properly, disclosure can be harmful to the person with HIV. Harmful disclosure includes disclosure of someone's HIV status without the consent of the person with HIV. This can have negative consequences for him or her, such as stigma, abandonment, physical violence, imprisonment, loss of job or housing, and other forms of discrimination. Harmful disclosure may also impact negatively on prevention and care activities. By driving people with HIV away from HIV services, fear of lack of confidentiality and forced disclosure also reduces the opportunities for positive prevention (UNAIDS/WHO 2000).

Shared confidentiality refers to the sharing of information, on a confidential basis, with the consent of the person with HIV and for their benefit. This applies, for example, to a healthcare worker confidentially sharing information regarding a person with HIV who is a patient to other healthcare workers involved in the management of the patient.

3.1 Individually focused health promotion

Strategy 3: Encouraging beneficial disclosure and ethical partner notification

Shared confidentiality can be used in a beneficial way for the person with HIV, but again can be harmful. Shared confidentiality has earned a bad reputation in India, where it is often transformed into an excuse for doctors to give HIV results to family members without any discussion or consent by the patient.

Ethical PN is encouraged by UNAIDS and WHO. While PN for STI has become accepted clinical practice in many industrialised countries, PN has not been used widely in HIV prevention. There is now emerging momentum to place greater emphasis on PN for HIV prevention – particularly by the CDC in USA with the promotion of SAFE (De Cock 2002; Fenton et al. 1997; Golden 2002; Janssen et al. 2001).

The historic lack of emphasis on HIV PN has often been related to a desire to avoid the harmful misuse of mandatory PN seen in some contexts where it is associated with coercion, legal duty to inform and lack of confidentiality (Fenton et al. 1997).

There is growing recognition that mandatory PN is not ethical, feasible or effective in achieving public health objectives. Most importantly, it appears that mandatory PN schemes are not necessary because voluntary PN schemes can achieve the HIV prevention goals. Moreover, voluntary PN strategies can help to create an environment of confidence that will attract people to VCT so that more people learn of their HIV status. Among those people with HIV who do come to healthcare facilities, it appears that most people agree to notify their partners on a voluntary basis after counselling *(UNAIDS/WHO 2000).*

A study in the USA found that partners who were contacted by health departments did not access care earlier. Rather, those people with HIV who tested anonymously then reported HIV cases voluntarily notified as many sexual and needle-sharing partners as those whose names had been reported to health departments *(Osmond et al. 1999).*

3.1 Individually focused health promotion

Strategy 3: Encouraging beneficial disclosure and ethical partner notification

Ethical PN is based on the informed consent of the people with HIV and, where possible, maintains the confidentiality of the source people with HIV so that their names are not revealed to the partner(s) being notified/counselled. This is extremely difficult to maintain in the context of marital relationships and requires the provision of counselling and support to both partners to reduce the possibility of abuse or discrimination. There are three main accepted methods for undertaking ethical PN, all of which are voluntary and confidential, and provided within the context of comprehensive HIV/STI prevention, care and support programmes:

1. **Patient/source referral,** in which people with HIV are encouraged to counsel partners regarding their possible exposure to HIV. This is done without the direct involvement of the healthworker. The healthworker works with the people with HIV regarding the nature of the information to be passed on, ways of doing it, and points out both the benefits and possible disadvantages of disclosure.

2. **Provider referral,** in which the people with HIV give their partners' names to a healthcare provider, who then confidentially counsels the partners directly. This approach is usually more successful than patient referral in reaching partners, but is more labour intensive and costly. Provider referral is especially useful for HIV patients who may have been infected for many years and who may have concerns about partners from a long time ago. Quite often such patients welcome offers by clinic staff to provide anonymous advice to such partners to seek HIV testing.

3. **Contract/conditional referral,** in which the healthworker of the people with HIV obtains the names of their sexual or injecting partners, but allows the people with HIV a period of time to counsel the partners themselves. If the partners are not counselled within this time period, the healthworker counsels the partners without naming the people with HIV source.

PN is often offered through clinic facilities, but other innovative approaches include:

Peer-assisted PN, for example where people with HIV in the Oasis clinic, Los Angeles, USA, successfully brought in peers for VCT (Jordan 2002).

Outreach-assisted PN is a service designed to promote, enhance and support the ability of a people with HIV to identify, locate and inform partner(s) of possible shared exposure to HIV.

3.1 Individually focused health promotion

Strategy 3: Encouraging beneficial disclosure and ethical partner notification

A community-based study in Chicago, USA, used a converted shop to provide counselling, testing and PN. The project used street outreach workers (former IDUs) to assist IDUs in notifying at least some of their sex or needle-sharing partners as part of the drug treatment recovery process. Assistance ranged from counselling in how to notify partners to providing outreach-assisted notification *(Levy and Fox 1999).*

In developing countries, the implementation of HIV PN programmes is particularly challenging due to poor infrastructure for the diagnosis and management of STD and HIV; limited resources to fund proactive referral programmes; strong social stigmatisation; and lack of access to new therapies. Nevertheless, HIV PN has been successfully incorporated into STD services in resource-poor settings. The provider referral PN method may be less feasible because of its high costs, although attempts have been made in Kenya to modify this method by directing counselling on PN towards groups of people who ordinarily tend to demonstrate higher rates of PN (STD, general outpatient, maternal and child health, family planning clinic patients) (Njeru et al. 1995).

Ethical PN also takes into account the serious consequence of people with HIV not being willing to notify their partners – possible HIV infection. This consequence requires healthcare providers to make ethical decisions based on the potential harms and benefits that are likely to occur if the client does not give consent to notify his/her partner(s). So, for example, if a man living with HIV refuses to notify his wife, following repeated efforts to persuade him to do so, and he is not practicing safe sex, the failure to notify creates a real danger of HIV transmission to his wife. In this situation, UNAIDS/WHO (2000) recommend that the counsellor should be authorised to notify his wife without the consent of the husband, after giving the husband reasonable advance notice of the counsellor's intention to notify the wife. In this case, the counsellor should arrange for follow-up social and legal support to prevent violence and family disruption.

Conversely, a wife living with HIV who wants to disclose her HIV status to her husband may not feel able to do so for fear of violence, stress, uncertain stability of relationship, abandonment (Stewart et al. 2000, South Africa), emotional trauma, blame and stigmatisation (Fenton et al. 1997; UNAIDS 2001). Counsellors need to be aware of this risk and take steps to reduce the possibility of violence before and after notification,

Strategy 3: Encouraging beneficial disclosure and ethical partner notification

using risk assessment tools, informing women of their rights, helping women develop a safety plan, and referring women to community resources. Violence reduction strategies need to be complemented at the community level too. Where risk of violence cannot be significantly reduced, partners should not be notified (e.g. Lindan 1990 in Rwanda; Population Reports 1999; Rothenberg et al. 1995; Zierler et al. 2000).

Evidence for the effectiveness of strategy 3 in positive prevention:
Most outcome evaluations of ethical PN strategies do not provide evidence on whether risk behaviour changed after disclosure or ethical PN, or whether new HIV infections were prevented. Rather, they assess the number of partners who were notified, who received VCT and who were found to be HIV positive (Fenton et al. 1997).

It can be implied that sharing an HIV test result with a sexual partner or partners can contribute to preventive behaviour change, since knowledge of a partners' sero-status can be a factor in the prevention strategies negotiated between partners (Schiltz et al. 2000). However, this link cannot always be assumed.

Findings from descriptive studies do indicate that HIV PN is effective in uncovering previously undiagnosed HIV infections. In general, current or more recent partners are most likely to be located and counselled through PN.

More research is clearly needed, since a review of various disclosure studies among MSM and bisexual men in industrialised countries concluded that disclosure can benefit people with HIV as part of adapting to living with HIV, but has a limited public health role in preventing further HIV transmissions (Summerside and Davis 2002).

The success of a PN strategy depends upon the setting in which it is undertaken and the population group, and how acceptable it is to people with HIV.

In settings where HIV is concentrated among core vulnerable groups, PN may be more cost-effective than other methods (e.g. mass promotion of VCT) since partners at risk of having HIV may be identified through sexual or drug-injecting networks (Giesecke et al. 1991, cited in Fenton et al. 1997). Further research is needed to confirm this.

Strategy 3: Encouraging beneficial disclosure and ethical partner notification

Usefulness of PN as an intervention to prevent HIV is uncertain in the context of high rates of partner change. However, it might play a part in assuring the safety of long-term sexual partnerships in high prevalence areas of low prevalence countries (De Cock et al. 2002).

Research in Ethiopia, Tanzania and Zambia found that people generally report that disclosing one's positive HIV status should be encouraged. However, in practice people with HIV disclose to a very limited number of trusted persons (ICRW 2002), and not necessarily to their sexual partners. Other studies in Africa show disclosure rates in the range of 24-79%, but with lower rates of partner testing (UNAIDS 2001).

Few studies have examined HIV disclosure patterns among IDUs to their sex and drug partners. One study in Baltimore, USA, found that IDUs living with HIV are more likely to disclose to social network members with whom they have strong ties, but were less likely to disclose to sex and drug partners who were HIV negative and potentially at risk of HIV infection (Latkin et al. 2001). However, no data was collected on changes in subsequent behaviour or disease outcomes.

Issues for consideration when adapting strategy 3:

Encouraging beneficial disclosure requires an environment in which more people are willing and able to get tested for HIV, and are empowered and encouraged to change their behaviour according to the results. This can be done by using other strategies for positive prevention, such as increasing availability and promotion of VCT, providing incentives to get tested in the form of greater access to prevention, community care and support services (including antiretroviral therapy) and removing disincentives to testing and disclosure by protecting people from stigma and discrimination.

Advocacy strategies with governments need to be combined with this strategy to create the conditions that encourage beneficial disclosure and ethical PN – laws and policies to protect against discrimination, and to protect confidentiality and informed consent.

An effective PN strategy depends upon health workers and counsellors who are well-trained in ethical PN, who understand the professional implications of informed consent and confidentiality, and who know the limited circumstances under which PN may take place without consent.

Strategy 4: Providing counselling for sero-discordant couples

Disclosure rates can be influenced by the views and approaches of counsellors. Often, counselling about disclosure is just a suggestion to disclose, whereas people with HIV need to have practical skills to share their status. Counsellors therefore need to be trained in communication and negotiation skills, role-playing and problem-solving (UNAIDS 2001).

More research is needed regarding the acceptability of HIV PN to people with HIV, their partners and to healthworkers, particularly when linked to named HIV reporting (as is the case in many American states) (Golden 2002).

STRATEGY 4: PROVIDING COUNSELLING FOR SERO-DISCORDANT COUPLES

Objective of Strategy 4:
To prevent the transmission of infection from the partner with HIV to the uninfected partner.

Description of Strategy 4:
Offering VCT to couples overcomes some of the difficulties of sharing test results, and may foster a sense of shared responsibilities in relation to risk reduction. Couple counselling and testing is aimed at enabling the couple to negotiate appropriate changes in sexual behaviour together. Couples seen together can be counselled to avoid blame, can make risk assessment and risk reduction plans together, and discuss childbearing decisions.

> Experience shows that couple counselling sessions should explicitly address sexual communication and decision-making, stigmatisation of partners living with HIV, sex positive approaches, support to the sero-negative partner, engaging the male partner, and negative reactions leading to marital violence or sexual coercion *(van der Straten et al. 1995 and 1998).*

Evidence for the effectiveness of Strategy 4 in positive prevention:
Couple pre- and post-test counselling has significant benefits for addressing risk assessment and risk reduction planning, especially for women in countries with marked gender inequalities. Research in Kenya, Tanzania and Trinidad and Tobago also indicates that targeting couples is more cost-efficient than targeting individuals (Sweat et al. 2000).

Strategy 4: Providing counselling for sero-discordant couples

Studies among sero-discordant couples in several high-prevalence African countries (Kenya, Rwanda, Uganda, former Zaire, Zambia) show that attending VCT together leads to consistent and significant reductions in risky sexual behaviour and prevents transmission to negative partners following VCT (UNAIDS 2001).

Some studies among heterosexuals in industrialised, low-prevalence countries, show that counselling of sero-discordant couples is very effective in preventing HIV transmission. For example, a study in San Francisco, USA, found that six-monthly couple counselling in combination with social support (a 'buddy' system, information nights, social gatherings) resulted in increased condom use and sexual abstinence by people with HIV and their heterosexual partners. Moreover, no HIV sero-conversions were observed in the study period (e.g. Padian 1993). However, the study methodology did not allow for a comparison of the effectiveness of the couple counselling alone compared to social support alone or in combination with couple counselling.

Despite evidence of some HIV-discordant couples reducing risk behaviours, many couples do continue to engage in unprotected sex, even after receiving intensive counselling (Gomez et al. 2002). Barriers to using condoms include the desire for sexual intimacy and trust, drug and alcohol use, and inability to negotiate condom use (Buchacz et al. 2001, in California Partners Study II; Summerside and Davis 2002).

In some contexts, uptake of couple counselling is low, especially when VCT services are first set up. Men and women may be reluctant to attend VCT together when cultural taboos prevent open discussion of sexuality, and when gender roles and relations hinder communication between the couple (Baggaley et al. 1997, Zambia).

There is an urgent need for evidence from sero-discordant couple studies in low-prevalence, developing countries using experimental research designs.

Issues for consideration when adapting Strategy 4:

Implementing couple counselling in low-prevalence areas is more difficult, where HIV infection is affecting MSM, SWs and IDUs disproportionately, since these groups tend to have higher numbers of less steady partners (sexual or injecting).

Couple counselling is much more difficult to implement where the nature of the relationship is casual or commercial (in the case of SWs). Couple-level strategies are better suited to counselling steady partners (Buchacz et al. 2001).

3.2 SCALING UP, TARGETING AND IMPROVING SERVICE AND COMMODITY DELIVERY

Strategies in this section are confined to those specifically tailored to the needs of people with HIV. This includes ensuring the availability of VCT, reviewing ART as a strategy for prevention, integrating positive prevention into treatment centres, reducing stigma in treatment facilities and providing services for preventing mother-to-child transmission 'plus' (PMTCT+).

STRATEGY 5: ENSURING AVAILABILITY OF VOLUNTARY COUNSELLING AND TESTING

Objective of Strategy 5:
To increase the number of HIV-infected persons who know their sero-status, in order to develop, maintain and sustain preventive and coping strategies.

Description of Strategy 5:
Access to VCT is now acknowledged to be a pivotal point of entry to both prevention and care services. VCT should comprise a number of inter-related services in order to be successful. These services include HIV pre-test counselling (including risk assessment), testing after informed consent is taken and post-test counselling.

Post-test counselling should include:

- referral to STI management
- family planning
- individual/couple, post-test counselling (including risk reduction planning)
- referral to ongoing counselling psycho-social and other support
- treatment for opportunistic infections
- access to ART
- access to MTCT initiatives.

In other words, VCT provides benefits for those who test positive as well as for those who remain negative. Within prevention programmes, VCT helps people learn about how HIV is transmitted, practise safer sex, get an HIV test and take steps to avoid STI infection, or onward transmission of HIV.

Strategy 5: Ensuring availability of voluntary counselling and testing

The design and implementation of VCT services must be tailored to the specific epidemiological, behavioural and socio-economic context of each setting, and should be combined with stigma reduction and demand creation interventions. A range of models for VCT service delivery exists, including:

VCT integrated within existing health facilities
(at antenatal, tuberculosis, family planning or STI clinics)
Freestanding VCT services
Mobile/outreach VCT services.

Each model has its own benefits and limitations (FHI Focus on VCT and Models of VCT Service Delivery 2001; Sozi et al. 2002). Studies demonstrate the feasibility of VCT in low-prevalence settings as well as high-prevalence settings.

Evidence for the effectiveness of Strategy 5 in positive prevention:
Evidence indicates that HIV testing on its own, in addition to being the first step toward receiving treatment and support, also promotes prevention-oriented behaviour. From a meta-analytic review by King-Spooner (1999) of 66 studies that included data on the effect of knowledge of positive status on preventive behaviours, nearly three-quarters of the studies reported people with HIV doing more than those not infected to prevent transmission (ie. sexual and injecting safety). This pattern was reflected in different populations (MSM, MSM drug users, heterosexual drug users, other heterosexuals), for sero-discordant and concordant couples, and for widely differing cultures (including UK, USA, Thailand, Uganda, Rwanda, Zaire). The pattern is less marked for injecting safety compared to sexual safety in drug users.

This argument is supported by studies that demonstrate a reduction in STDs in people who learn of a positive HIV status rather than a negative status (Cleary et al. 1991; Zenilman et al. 1992).

Some NGO services in India report increase in condom use following VCT (Kalayanasundaram 1998, cited in UNAIDS 2001).

Despite these findings, many studies also demonstrate that a substantial minority of HIV-positive people report that they have unprotected sex with partners who are not HIV-positive or do not know their sero-status (Summerside and Davis 2002). This justifies the need for additional prevention strategies tailored to people with HIV.

Strategy 5: Ensuring availability of voluntary counselling and testing

All but a few of the above studies were descriptive in design, without control groups, and relied on self-reported outcomes.

There is strong evidence that VCT is effective and cost-effective as a strategy for facilitating behaviour change of people with HIV. In the first and most recent randomised trial of VCT, 3120 individuals and 586 couples in the capital cities of Kenya, Trinidad and Tobago, and Tanzania were randomly assigned to either a VCT group or a basic health education group, with the option for VCT provided as follow-up a year later. VCT was based on CDC's client-centred HIV-1 counselling model, which includes personalised risk assessment, development of a personalised risk-reduction plan for each client, and can be used to tailor culturally appropriate responses. The VCT group self-reported a 35% reduction in unprotected sexual intercourse with both steady and casual partners during the year following the initial VCT, compared with only a 13% reduction in the group that received basic health information (The Voluntary HIV-1 Counselling and Testing Efficacy Study Group 2000). VCT was found to be highly cost-effective in these urban, high-prevalence contexts, but slightly less so than STD treatment and universal provision of nevirapine for PMTCT (Sweat et al. 2000).

Moreover, the same study found that people with HIV – women and men – were more likely than sero-negative people to reduce unprotected intercourse with steady and casual partners (men) and steady partners only (women).

A similar impact of VCT on self-reported risk reduction was established in urban and rural routine health centres in Kenya (Arthur et al. 2002).

In a lower prevalence setting, a study from Bangkok compared self-reported behaviour of sero-positive people who had received VCT at the Thai Red Cross Immune Clinic with those from a matched sample of sero-positive people who were unaware of their status. Of the people who had received VCT, 84% reported that they had decreased their number of sexual partners since receiving it, and reported more frequent condom use and more frequent abstinence than those not aware of their sero-status (Muller et al. 1995).

Most of the more rigorous study designs in low-prevalence contexts are from industrialised countries and among MSM and IDU groups. Although many of these studies show reductions in risky behaviour following VCT, the results are not consistent. For example, studies among IDUs in Puerto

Rico (Colon et al. 1996) and Thailand (Kawichai et al. 2000) found no significant difference in injecting risk behaviours between those who had VCT and those who had not. However, the Puerto Rican study did demonstrate safer sexual behaviour among sero-positive IDUs following VCT than among those not infected or of unknown sero-status. Other social and behavioural factors may be important in determining sexual and injecting behaviour in these groups, and findings cannot be generalised to heterosexuals in developing countries (UNAIDS 2001).

Very few studies among SWs in developing countries have been undertaken. Most of these studies have shown that VCT can be acceptable to female SWs, and some result in behaviour changes such as condom use. But in many settings, economic pressures and marginalised social status prevent SWs from practicing safe sex, even after testing HIV-positive. Increased efforts to reach their clients and to work with the gatekeepers are needed. Innovative, tailored approaches to increasing access to VCT for SWs are also required; e.g. VCT outreach buses (UNAIDS 2001).

Some studies among heterosexuals in industrialised countries provide at least some evidence of VCT motivating risk-reducing behaviour, but others do not. VCT in STI clinics and among students were found to have only limited effect in changing behaviours (UNAIDS 2001).

Although several studies show that VCT is more effective in changing behaviour than health education, and in-depth counselling superior to brief information-giving, it is not known what are the key elements of VCT that are most important in motivating long-term behaviour change (UNAIDS 2001).

There is very little information on whether behaviour changes in those who test positive can be maintained in the long term (UNAIDS 2001). More longitudinal, experimental studies are needed in developing countries to explore the impact of VCT on risk behaviours and STI incidence in people with HIV, whilst taking account of the sero-status of the sexual partner, the partner type (regular/casual), and the type of risk behaviour.

Strategy 5: Ensuring availability of voluntary counselling and testing

Issues for consideration when adapting Strategy 5:

A comprehensive VCT service can have considerable benefits, but a partial service could result in individual frustration and suffering and lead to community resentment. VCT needs to be part of a comprehensive programme that provides ongoing prevention information and counselling tailored to the needs of specific groups.

Organisations should not underestimate the difficulties of implementing an effective VCT intervention. Quality is harder to ensure when a number of services are integrated.

In countries with lower HIV prevalence, stand-alone VCT service delivery may be less cost-effective than VCT services integrated into existing health facilities, since relatively few people will think they might be infected and because there is likely to be a high level of stigma attached to coming forward for VCT. For example, the YR Gaitonde Center for AIDS Research and Education walk-in clinic in Chennai, India, provided anonymous and confidential testing to just 1,745 clients over a 4.5-year period (Solomon et al. 2000).

Confidentiality must be maintained, and testing could be anonymous, although emphasis on anonymity should lessen as HIV testing becomes viewed as a normal event (De Cock et al. 2002).

VCT services must be targeted for specific groups, such as couples and young people, and for populations such as IDUs, MSM, SWs where they are significant to epidemic dynamics. Targeting provides the opportunity to receive counselling (from peers) about safe behaviours. For example, a study of 5,644 IDU attendees at a needle-exchange and detoxification centre in California, USA, found that the factor most closely associated with not sharing syringes was use of VCT services (UNAIDS 2002).

Finding enough trained counsellors can be a major challenge to the expansion of VCT services. Due to a shortage of nurses or social workers, counsellors also need to be drawn from other backgrounds.

Strategy 5: Ensuring availability of voluntary counselling and testing

UNAIDS (2002) provides suggestions for various levels of counsellors, with different roles, training and responsibilities:

A Peer Counsellor (including people with HIV, such as women who have been through PMTCT projects, youth peer counsellors) is responsible for advocacy and community mobilisation, HIV education and preventive counselling, supportive counselling for uncomplicated cases, running support clubs.

A Lay Counsellor, with pre-/post-test and ongoing counselling training, is responsible for pre- and post-test counselling of routine cases and supportive counselling for uncomplicated cases.

A Professional Counsellor provides pre- and post-test counselling, couple counselling, follow-up counselling and support for lay and peer counsellors.

A Senior Counsellor with advanced counselling training supervises the other counsellors, trains other cadres of counsellors, accepts referral of complex cases and supervises support clubs.

Another approach to dealing with a lack of trained counsellors is to provide general HIV education and pre-test counselling to groups of clients, particularly in antenatal clinics. Post-test counselling must always be provided on an on individual or couple basis. This approach has been effective in Uganda, where AIDS Information Center counsellors were posted to the national referral hospital to counsel pregnant women about HIV and PMTCT (Kibenge et al. 2002).

Use of simple, rapid tests that can be performed without laboratory support is important for making HIV testing more accessible to rural areas. This provides opportunities to increase dramatically the availability of HIV testing in a variety of settings where large numbers of people at risk may congregate. Also for voluntary testing and counselling in emergency rooms, STD clinics, drug detoxification units and prisons.

> **"** Recent advice to people with HIV from AIDS Service Organisations in the UK and USA conclude:
> We can be reasonably confident in asserting that there is some level of benefit [of ART] to the community in reducing HIV transmission as a result of lower HIV viral loads in large numbers of HIV-positive individuals. For many individuals, there is probably some real reduction in the transmission risk from a given unprotected contact. The problem is, we have no way as yet of knowing for whom this is true and for whom it is not! **"**
>
> *Senterfitt in Being Alive Newsletter, November 2001*

> **"** An undetectable viral load does not mean there is no HIV in your blood ... There may be lower risk of HIV transmission if your viral load is undetectable, but a lower risk is not zero risk ... Using your viral load test results to make decisions about the kind of sex you have is a very undependable way of avoiding HIV transmission. **"**
>
> *Terrence Higgins Trust Briefing Sheet on Viral load and infectiousness: issues for people with HIV, September 2002*

STRATEGY 6: PROVIDING ANTIRETROVIRAL TREATMENT FOR POSITIVE PREVENTION

Objective of Strategy 6:
To prevent onward HIV transmission by decreasing the infectiousness of people with HIV.

Description of Strategy 6:
Sexual Behaviour Still Matters Most

Provision of ART for positive prevention: Hopes have been raised recently that the risk of transmission from people with HIV with viral loads suppressed by ART may be lower than the risk of sexual transmission from those who are not receiving ART. If this is true, then ART not only prolongs life and improves quality of life of people with HIV, but may also slow the spread of the disease in the population. Data on viral load in pregnancy also support the notion that HIV viral load is a major determinant of transmission.

Although it is biologically plausible that effective use of ART would reduce viral loads in vaginal fluids and semen, and as a result reduce sexual transmission, no studies have yet demonstrated this at the population level (FHI 2001).

At an individual level, there are two factors that complicate the relationship between viral load and infectiousness. First, HIV can be present in other body fluids apart from blood, including the brain, semen and vaginal fluids; some people with HIV have relatively high viral loads in their semen while having relatively low viral loads in their blood, and vice versa. Second, viral loads can rise and fall over time, even during one day. Both these factors mean that individual people with HIV should not assume that ART reduces infectiousness and sexual transmission of HIV. However, there is an overall effect (averaged across people with HIV) that ART reduces genital as well as blood viral load (King 1997; Senterfitt 2001).

3.2. Scaling up, targeting and improving service and commodity delivery

Strategy 6: Providing antiretroviral treatment for positive prevention

> ART for prevention is very much an area of ongoing controversy, debate and research, with no definitive conclusions reached about the potential of ART as a positive prevention strategy. Further, no information is yet available regarding the ways these dynamics might operate in developing countries *(Marseille et al. 2002)*. In the meantime, there is consensus that the introduction of ART must be accompanied by vigorous and targeted prevention education, counselling and risk reduction strategies.

There are also growing concerns – at least in industrialised countries – that the wide availability of ART is creating false hope by lessening the perceived severity of HIV/AIDS ('treatment optimism'), leading to increased risk-taking among people with HIV and those uninfected, which could outweigh the potential prevention benefits of ART. This concern is exacerbated by the fact that people with HIV receiving ART are likely to live longer and therefore have a longer time period in which to take risks and to transmit potentially drug-resistant strains of HIV. These concerns underline the need to include positive prevention as an essential component of the provision of ART.

Evidence for the effectiveness of Strategy 6 in positive prevention:
The effects of ART on infectiousness could best be displayed graphically using data from Quinn's paper (NEJM 2000; 342: 921).

Recent findings from Uganda indicate that the risk of transmission within sero-discordant couples is highly correlated with HIV viral load in the blood (Gray et al. 2001; Quinn et al. 2000). These findings have been used to suggest that ART, by reducing a positive person's HIV viral load, may decrease infectiousness; i.e. the chances of sexual transmission.

However, it is difficult to apply the Uganda findings directly to the situations of people treated with ART; firstly, because the study was conducted with people with HIV who were not receiving ART, and secondly, because there may have been other factors that accounted for these findings (Senterfitt 2001).

For ethical reasons, there are no experimental studies with control groups to assess direct cause and effect of ART on onward HIV transmission.

Strategy 6: Providing antiretroviral treatment for positive prevention

The timing of starting ART will also make a difference to the potential preventive effect of ART. Often people with HIV do not access ART until symptoms begin to appear. However, symptoms occur after the very early phase of infection, which is the period when a large proportion of HIV transmission occurs (Marseille et al. 2002).

With regard to 'treatment optimism', causal explanations are lacking in existing research findings which are mostly based on observational, correlational studies conducted at one point in time, rather than assessing how sexual behaviour changes over time.

In Australia (Van de Ven et al. 1999), France (Adam et al. 1998), the UK (Hickson 1998), USA (Remien et al. 1998; Vanable et al. 2000) and Canada (Kravcik et al. 1998), there is evidence that increased optimism about treatment for HIV since the advent of ART is beginning to impact negatively on MSM's perception of the need to take protective measures when having sex. This was not found to be the case for heterosexual men and women (Miller et al. 2000).

A study among MSM in Amsterdam also found that infection rates of rectal gonorrhoea and early syphilis increased, coinciding with the introduction of ART (Stolte et al. 2001).

On the other hand, a small study of HIV positive youth in three American cities found no evidence that using ART is associated with increased risk behaviour. To the contrary, highly adherent users of ART were more likely to report fewer risky behaviours. (Etzel et al. 2002). However, this study relies on retrospective self-reporting of behaviours and the analysis did not necessarily take account of confounding factors.

A study in Italy provides no evidence that the initiation of ART has any role, at least in the short term, in increasing sexual risk-taking behaviour of MSM living with HIV (Aloisi et al. 2002).

For more data on HIV risk behaviour in men on ART, (see Imrie et al. Feb. 2003). This study did not show increases in risk.

While the availability of ART might well be a contributing factor to reducing safe behaviours, other explanations warrant further exploration: the visibility of prevention efforts directed at MSM has decreased in recent years, along with the prevention and treatment of other STIs; prevention campaigns may have become too generic, and not targeted

sufficiently at MSM or people with HIV; or younger men may find the prevention messages developed by and targeted at older groups less relevant (UNAIDS 1999 and 2002).

Evidence from developing countries is scarce, but a recently reported 3.7% increase in HIV incidence in Brazil – where ART is provided for free to all citizens with AIDS – was attributed to decreased condom use in young MSM (cited in Marseille et al. 2002).

However, there is contradictory evidence from a cross-sectional survey among 800 MSM in seven Brazilian cities. This found that the prevalence of reported condom use in this sexually active group of MSM – for both people with HIV and people who are not infected – remains high in an era of widely available ART (Bacon et al. 2002).

A recent study in Chile also concludes that increasing access to ART does not by itself increase sexual risk behaviours among people with HIV. The study among 800 people with HIV, including over 400 MSM, found that people treated with ART are more often sexually abstinent in the last 12 months than untreated people; they report fewer sexual relationships and use condoms more consistently (Sgombich et al. 2002).

Issues for consideration when adapting Strategy 6:

Where ART is introduced as a treatment strategy, clear communication will be required for communities at large and for people with HIV to avoid misunderstandings and to clarify these complex issues around ART as a potential prevention strategy. Already, confusion is growing among even the most well-informed people with HIV (see PWHA-NET mailings) and in places where ART is not even widely available.

Even if it is assumed that ART is not an effective positive prevention strategy, linkages to HIV prevention strategies for people with HIV should be an integral part of scaling up access to ART as a treatment strategy in resource-restricted settings (Lackritz et al. 2002).

Longitudinal studies, conducted with key populations in low-prevalence countries, are needed to explore: the ethical and patient management implications of ART for prevention purposes (e.g. FHI's Work Positive Assistance Project); the effect of scaling up availability of ART on stigma and discrimination; and the effect of introducing ART on protective and preventive behaviours of people with HIV and their partners (Horizons 2002; Gilks 2001; Summerside and Davis 2002).

3.2. Scaling up, targeting and improving service and commodity delivery

Strategy 7: Reducing stigma and integrating Positive Prevention into treatment centres

Consideration needs to be taken of the idea that treatments impact in various ways on sexual behaviour by affecting sexual confidence, interest in sex and libido in varied ways (Summerside and Davis 2002).

Practical and ethical guidance on introducing ART into resource-constrained settings is provided in the Alliance's *Handbook on Access to HIV/AIDS-related treatment: a collection of information, tools, and resources for NGOs, CBOs and people with HIV groups* (2002).

STRATEGY 7: REDUCING STIGMA AND INTEGRATING POSITIVE PREVENTION INTO TREATMENT CENTRES

Objective of Strategy 7:
To remove healthcare providers' stigma as a barrier to positive prevention opportunities and to build capacity within treatment centres to respond to the prevention needs of people with HIV.

Description of Strategy 7:
Visits by people with HIV to treatment centres are good opportunities for positive prevention. Often there is not the capacity for this and in addition, people with HIV may feel stigmatised by healthcare providers, resulting in a reluctance to attend treatment centres.

Training of healthcare providers in positive prevention.
Healthcare providers are busy and often miss opportunities to talk to people with HIV about practicing safer sex and disclosure.

A study in six public HIV clinics in California, USA, found that over 50% of people with HIV patients were not counselled about self-disclosure and 30% were not counselled about safer sex *(Marks et al. 2002).* Missed opportunities are even more likely to be the case for healthcare providers in resource-constrained settings, and where enhanced stigma prevents open discussion between the people with HIV client and healthcare provider.

To address this situation, healthcare providers require training in supporting people with HIV to build prevention skills and to refer them to

Strategy 7: Reducing stigma and integrating Positive Prevention into treatment centres

appropriate prevention services. In this way, consultations for STI treatment or treatment for opportunistic infections can be reoriented to address the sexual well-being and HIV/STI prevention needs of people with HIV.

Locating trained counsellors in treatment centres can relieve the burden on healthcare providers, who do not then have to become skilled counsellors themselves. These trained counsellors located in treatment centres can also where possible be peers (with HIV and/or from a particular vulnerable group) and can provide a wide range of referrals and introductions to other community-based care and support services.

Even if health providers are trained in positive prevention strategies or peer counsellors available, people with HIV will only benefit from their knowledge if they are able to access treatment in the first place. However, experience from many countries indicates that discrimination by healthcare providers is a major barrier to people with HIV seeking or obtaining treatment. For example, a health-seeking behaviour study in New Delhi, India, found that people with HIV faced denial of treatment, delayed treatment, segregation and isolation from other patients, and early discharge (Panda et al. 2002).

One approach to reduce stigma in order to develop a more 'patient-friendly' hospital has been the use of a self-assessment achievement checklist (Gilborn et al. 2002). The assessment covers policies and practices regarding confidentiality, informed consent, HIV testing and counselling, infection control and universal precautions. The sources of information are observations and healthcare worker interviews. An action plan is then developed from the identified institutional strengths and weaknesses, and 'gold standards' are set.

Evidence for the effectiveness of Strategy 7 in positive prevention:
The Achievement Checklist has been shown to foster positive change in a hospital in New Delhi. The tools piloted led to institutional changes in HIV counselling practices, healthcare worker training and sensitisation, reader-friendly hospital policy guidelines on HIV/AIDS care and management, and policies on mandatory testing and HIV/AIDS. Managers were engaged in this process through the collection of facility data.

Not only are these changes assumed to improve the services for people with HIV, but they also help establish safer working conditions for healthcare providers through improving communication materials on

infection control and training all workers in universal precautions. This in turn is expected to reduce fear of infection on the part of health providers and thereby to reduce discriminatory attitudes and actions (Parker and Aggleton 2002).

Further evaluations are required to assess the extent to which changes in the 'friendliness' of a facility encourage better use of prevention and care services by people with HIV, and lead to fewer instances of felt stigma and discrimination by people with HIV.

Issues for consideration when adapting Strategy 7:
Healthcare providers are real people, embedded in social and cultural contexts as much as the people with HIV they are treating or counselling. Health workers need space to reflect on and discuss their own fears, prejudices and views, and to become comfortable with discussing sex, injecting drug use and sexuality. They need support with ethical issues, such as how to respond to a woman living with HIV who refuses to use condoms because of her strong desire for children.

Training should ensure that healthcare providers develop non-judgemental attitudes, seek to understand the reality of living with HIV and sexual practices, and seek to support the adoption or maintenance of safer practices in ways relevant to the circumstances of people with HIV (Terrence Higgins Trust, Dec. 2002).

Improvements in services need to be paralleled with improved involvement of people with HIV in the design and delivery of services. To fail to do so may contribute to further discrimination, unmet health and social needs, and missed opportunities to address prevention issues.

It should not be forgotten that some healthcare providers themselves might be living with HIV, which presents additional challenges such as guilt due to fear of infecting patients when infection control procedures are lacking, or difficulties in counselling patients if it is not possible for them to be open about their own status. Counselling, further training on AIDS care and management, and a supportive working environment can help them adapt to these challenges (O'Keefe et al. 2002).

Strategy 8: Providing services for preventing mother-to-child transmission

STRATEGY 8: PROVIDING SERVICES FOR PREVENTING MOTHER-TO-CHILD TRANSMISSION

Objective of Strategy 8:
To prevent onward vertical transmission of HIV from mother to infant, and to care for HIV-positive mothers.

Description of Strategy 8:

The United Nations agencies recommend a three-pronged strategy to prevent transmission of HIV to infants *(WHO 2001)*:
1. Primary prevention of HIV among parents-to-be, including IEC, condom promotion, VCT to include pre-conceptional counselling, STI treatment and community action to reduce stigma and discrimination.
2. Prevention of unwanted pregnancies among HIV-infected women, including the programme components above plus reproductive health and family planning services. Such services should ensure that women can choose whether or not to know their HIV status; to control their fertility; or to terminate a pregnancy, where this is safe and legal.
3. Prevention of HIV transmission from HIV-infected women to their infants through the provision of antiretroviral drugs to HIV-infected pregnant women and their infants, safe delivery practices (including elective ceasarean section), and counselling and support for safer infant feeding practices.

The use of preventive antiretrovirals
Many different clinical trials of various drug regimens have been and are being developed, starting at different stages (antepartum, intrapartum, postpartum) and in breastfeeding and non-breastfeeding populations (see summary in WHO 2001 and UN Regional Task Force 2001). Short-course zidovudine is widely used in MTCT pilot projects in resource-constrained countries, and acceptance rates are increasing following a successful trial in Thailand. Many programmes use nevirapine, based on the results of the HIV NET 012 study in Uganda. Given as a single dose to the mother at delivery and a dose to the child within 72 hours of birth, nevirapine is similar in effectiveness to short-course zidovudine and is less costly. Trials are now underway to see if giving ARV drugs to infants for a longer period after birth will further reduce transmission.

Strategy 8: Providing services for preventing mother-to-child transmission

Avoidance of unnecessary invasive procedures during labour and delivery also benefits all pregnant women, and may reduce MTCT regardless of whether HIV status is known (UNAIDS 2002).

Replacement feeding
It is increasingly clear that breastfeeding undermines the protective effect of ART to prevent MTCT.

> The UN Interagency Task Team on MTCT of HIV recommends that when replacement feeding is acceptable, feasible, affordable, sustainable and safe, HIV-infected mothers should avoid all breastfeeding. Otherwise, exclusive breastfeeding is recommended during the newborn's first months of life. All HIV-infected mothers should receive counselling, including provision of general information about the risks and benefits of various infant feeding options, and specific guidance in selecting the option most likely to be suitable for their situation. Whatever a mother decides, she should be supported in her choice.

Planning for the long-term care and support of HIV-infected and affected children in the family is also important.

> A recent initiative in sub-Saharan Africa, 'MTCT-Plus' seeks to expand services for HIV-positive women, including basic care for prevention and/or treatment of opportunistic infections and, when indicated, treatment with antiretrovirals. The hope is that eventually, MTCT-Plus will include the HIV-positive family members of participating mothers and children. The initiative includes information campaigns to raise international awareness, along with the purchase and distribution of drugs to prevent MTCT, advocacy for the elimination of laws and regulations that delay access to drugs, and education and training programmes *(UNAIDS 2002).*

3.2. Scaling up, targeting and improving service and commodity delivery

Strategy 8: Providing services for preventing mother-to-child transmission

Evidence for the effectiveness of Strategy 8 in positive prevention:
To date, there is no evidence on the effectiveness of MTCT-Plus reducing HIV morbidity and mortality in mothers.

Rather, evidence has focused on the efficacy of different antiretroviral regimens for MTCT prevention in terms of reducing HIV transmission rates in infants.

The HIV NET 012 study demonstrated that use of single-dose nevirapine resulted in a reduction of 47% in the numbers of HIV-infected infants who were breastfed. (14-16 week efficacy). Short-term safety and tolerance of single-dose nevirapine have been demonstrated in clinical trials.

Completely avoiding breastfeeding eliminates the risk of transmission through breastmilk (which accounts for about one-third of HIV transmissions from mother to child). Without ARV or replacement feeding, between 25-45% of infants become infected. With ARV but no replacement feeding, between 17.5–32.5% of infants become infected. With ARV and replacement feeding, between 7.5–12.5% of infants become infected (DFID 2001).

Antenatal administration of Vitamin A and other micronutrients has no demonstrable effect on MTCT (DFID 2001).

Research has shown a 50% reduction in MTCT if elective caesarean section is carried out before labour and before membrane rupture (Newell 2001). However, any caesarean delivery carries risks of sepsis and delayed wound healing, and requires an effective, high-quality referral system. For a woman whose immune system is compromised by HIV/AIDS it is particularly unsafe.

A trial of chlorhexidine wash of the birth canal showed no reduction in MTCT except in a sub-population with prolonged rupture of the membranes. More research is needed to determine whether or not this intervention decreases neonatal morbidity and mortality. Trials are being planned to investigate whether antibiotic prophylaxis against infection of the membranes can reduce MTCT, without accelerating the development of antibiotic resistance (DFID 2001).

Strategy 8: Providing services for preventing mother-to-child transmission

Issues for consideration when adapting Strategy 8:

Only 1% of women in need of prevention of MTCT services have access to these services in sub-Saharan Africa (Global HIV Prevention Working Group 2003). This illustrates the considerable challenge in providing access to these type of services.

Discrimination against positive pregnant women is a major barrier to prevention of MTCT services uptake. For example, a study in India (Mumbia and Sumerpur) found that a high proportion of pregnant women who were screened for HIV at antenatal clinics were discriminated against in the form of abuse, beatings and even abandonment by their husbands. Pre-test counselling is critical in this context, for couples and not just the pregnant mother, alongside HIV screening (Shah and Shah 2000).

The above point illustrates the importance of community involvement in PMTCT strategies, of involving the community in designing effective and appropriate services and messages for PMTCT and of combining PMTCT with interventions to reduce stigma, provide social support for women and ensure ongoing dialogue between health service providers and the community. The acceptability of PMTCT interventions to the community also needs to be monitored and evaluated (e.g. through community advisory committees representing women and men) (ICRW 2002).

Access to MTCT prevention programmes is determined mainly by the capacity of the health system to make the relevant services available in a way that is convenient and affordable to those who need them. Health systems with lower capacity may need to focus on primary prevention while strengthening their existing services in order that they can carefully phase in the introduction of VCT and MTCT prevention measures.

Coverage and impact of programmes are also affected by whether women come forward to take up the services that are available. This starts with uptake of VCT as a critical entry point to PMTCT programmes. As noted earlier, many social and system factors affect uptake. Men can play important roles in increasing acceptance and uptake, so innovative ways must be sought to encourage their greater participation in VCT and PMTCT. Encouraging more men to accept an HIV test is an important first step in getting them to take more responsibility for PMTCT, including using condoms during the pregnancy and being supportive of HIV-positive women's infant-feeding choices. Couple counselling is especially useful in this regard.

Strategy 8: Providing services for preventing mother-to-child transmission

PMTCT programmes raise several ethical and human rights issues. For example, PMTCT programmes should enable women to make informed choices concerning all the interventions on offer and their decisions should be supported. Resource allocation is an ethical as well as a rational issue. The potential benefits to be gained from alternative uses of scarce resources should be considered and weighed against other public health priorities.

Any donation of infant formula or other breast milk substitute must comply with the International Code of Marketing of Breast milk substitutes.

In many settings, women who do not breastfeed are stigmatised. Programmes that include promotion of replacement feeding must take into account the social context and include measures to mitigate possible negative social consequences. Prevention of MTCT programmes can also inadvertently promote mixed feeding rather than replacement feeding. For example, in a pilot project in Uganda, a high proportion of mothers who accepted free infant formula at the time of delivery failed to return later to collect further supplies.

The choice of regimen(s) to be included in a MTCT-prevention programme should be determined by assessment of feasibility, efficacy, acceptability and cost. Factors to be considered include: availability of VCT services; proportion of HIV-infected women who are aware of their sero-status at different stages of pregnancy; patterns of initiation of antenatal care; frequency of antenatal visits; quality of antenatal care; proportion of births occurring in healthcare facilities; access to early postnatal care; acceptability and ease of dosage schedules; access to and cost of drugs. It should be noted that drug costs may represent only a fraction of the costs of the services that are required for an effective MTCT-prevention programme (WHO 2001).

There are concerns over drug resistance in women and children who have access to ART. The clinical significance of the emergence of drug resistance in the context of MTCT prevention programmes is as yet unknown, particularly with regard to future treatment options for the mother or the child, or to the outcome of prophylaxis during a subsequent pregnancy if the same drug is used. WHO concluded that the benefit of decreasing MTCT with these regimens outweighed concerns related to development of drug resistance (WHO 2000).

> *ARVs are not the only solution; we need the support and respect of the community. We sometimes forget the essential ingredient in a community response is a willing community.*
>
> *Delegate at 12th ICASA, December 2001*

3.3 COMMUNITY MOBILISATION

People living with HIV are part of and influenced by the broader community within which they live. If people with HIV are to prevent onward transmission, they need the support of the wider environment to enable them to adopt and sustain the safer behaviours encouraged by the individually focused health promotion strategies. This calls for collective responsibility by leaders and society, in addition to people with HIV's individual responsibility. Initiatives to nurture collective responsibility are required at the community level as well as state and national levels. The following strategies aim to achieve social and community change to complement individual behaviour change.

Priority is given to approaches that aim to strengthen capacity for mobilisation among stigmatised and marginalised groups – in this case people with HIV. Empirical evidence indicates that some of the most effective responses to the HIV/AIDS epidemic have been those where affected communities have mobilised themselves to fight stigma, discrimination and oppression (Parker and Aggleton 2002). These strategies operate at what some authors call the 'environmental level' (Sweat and Denison 1995). Some of these strategies overlap with and complement advocacy, policy and community awareness strategies. It should be noted that community mobilisation activities need to be designed to ensure a maximum impact on prevention, by enhancing the prevention-care linkages. Also that the evidence base on community mobilisation strategies for positive prevention is very limited in both industrialised and developing countries.

STRATEGY 9: FACILITATING POST-TEST CLUBS AND OTHER PEER SUPPORT GROUPS

Objective of Strategy 9:
To provide safe spaces to help people with HIV cope following VCT, by sharing experiences and providing mutual support.

Description of Strategy 9:
Peer support groups and post-test clubs can be developed in association with VCT services. As well as providing forums for support and sharing with a group of people with HIV, they can also become a platform for advocacy, to improve services and challenge legal or policy decisions. Some groups provide outreach HIV education to the community. As part

Strategy 9: Facilitating post-test clubs and other peer support groups

of the support function, post-test clubs provide an opportunity to support people with HIV to appreciate their role in prevention efforts, to discuss positive prevention strategies, sex-positive approaches, and issues around disclosing one's status with others. These groups also provide social support networks for people with HIV.

> For example, the Wednesday Friends Club in Bangkok for women and men with HIV/AIDS *(UNAIDS June 1999)*; Companions on a Journey in Sri Lanka for MSM; Naz Foundation (India) Trust Care Centre support group for women, men, children *(De Melo 2002)*; Group of Support and Prevention of AIDS in Brazil.

Women living with HIV often need particular support to address specific issues such as getting their men to practice safer sex, telling their sero-status to partners and children, and self-help schemes to reduce dependency on male partners.

> Resources such as 'Positive Women's Survival Kits' can be helpful (GNP+ 2001), as can networking opportunities just for women, such as National Community of Women Living with HIV/AIDS in Uganda *(Kasolo et al. 1998)* and Positive Women Network of South India *(Augustine 2002).*

Evidence for the effectiveness of Strategy 9 in positive prevention:
There appears to be extremely little published evidence on the effectiveness of post-test clubs, particularly in terms of helping them adopt and sustain safe sexual or injecting behaviours for prevention. Most studies that do exist are in high-prevalence countries and focus on the benefits of social support for coping with living with HIV (e.g. Katongo 2000 in Zambia; TASO Uganda studies).

One exception is the assessment of the impact of a support group formed by the Brazilian Network of people with HIV on quality of life measures of male and female support group members. Prior to support group meetings, 37% of participants expressed adequate knowledge of HIV prevention, and this rose to 88% after three months of weekly group meetings (Mello 2002). Unfortunately, no data was collected on changes in behaviour.

Strategy 9: Facilitating post-test clubs and other peer support groups

A study among HIV-positive MSM in the USA found that attending support groups increased disclosure. While disclosure is not a preventive behaviour in itself, it is related to safer sexual behaviour (De Rosa and Marks 1998).

Post-test clubs are likely to face greater resistance in low HIV-prevalence contexts due to heightened stigma and discrimination, and the likelihood that those living with HIV are already highly marginalised in society. More research is needed into the feasibility and effectiveness of people-with HIV support groups in these settings.

Issues for consideration when adapting Strategy 9:

Problems of coverage and sustainability are common (UNAIDS 2001), although a feature of mutual support is generally that groups are dynamic with a high turnover as people with HIV move on to more mainstream coping and support mechanisms.

In low-prevalence contexts, where HIV is concentrated among very vulnerable groups, providing specific peer support groups for people with HIV involved in commercial sex, drug injecting, or MSM are needed. Peer support groups have also been piloted for prisoners living with HIV; for example, in Mexico (Baeza 2002).

For further information, see the GNP+ manual *Positive Development: setting up self-help groups and advocating for change*. This is a manual for people living with HIV/AIDS.

3.3 Community mobilisation

Strategy 10: Implementing focused communication campaigns

STRATEGY 10: IMPLEMENTING FOCUSED COMMUNICATION CAMPAIGNS

Objective of Strategy 10:
To raise awareness about the role of women and men living with HIV in HIV/STI prevention and enable people with HIV to reduce risk behaviours.

Description of Strategy 10:
Communication campaigns directed at people with HIV have been used successfully in the USA.

A CDC-funded campaign HIV Stops with Me in San Francisco featured HIV-positive people in advertisements in newspapers, magazines, postcards and on television. An interactive website was also used. The main message of the campaign was that it takes a positive person to infect a negative person with HIV.

Similarly, the Positive Images programme was set up in 2001 by the multicultural Los Angeles Consortium of AIDS CBOs. This programme aims to:

- Raise awareness about the role of people with HIV in HIV/STI prevention
- Provide social networks that promote self-esteem and self-efficacy to practice safer sex
- Encourage people with HIV to reduce their risk for co-infection with other STDs
- Promote HIV testing (see also Strategy 1).

Positive Images uses the mass media as well as a free anonymous telephone chat line, internet website and chat room facilitated by trained people with HIV peers from various cultures, both women and men. The telephone chatline gives people with HIV the opportunity to talk anonymously about their feelings concerning sex and safe drug use. The internet chat rooms provide opportunities for group discussion among people with HIV peers, such as women or gay Asian men. In this way, social networks are formed which provide a sense of solidarity for people with HIV. In addition, the programme aims to reach people who have HIV, but who are unaware of their status *(Collins et al. 2000; Olufs 2001).*

3.3 Community mobilisation

Strategy 10: Implementing focused communication campaigns

Evidence for the effectiveness of Strategy 10 in positive prevention:
An evaluation of the 2000 HIV Stops with Me advertisement campaign showed that 19% of gay and bisexual men living with HIV reported that they were more likely to use condoms during intercourse with HIV-negative or unknown status partners after seeing the advertisements. This rose to 40% after 2001 campaign (Bajko 2002).

No evaluation appears to be available for the Positive Images programme.

Further research is needed to assess whether reductions in risk behaviour and new cases of STI do actually occur following the campaigns.

Issues for consideration when adapting Strategy 10:
The HIV Stops with Me campaign caused great controversy since it was the first time that an HIV campaign had focused on people with HIV. The advertisements were only allowed to be shown on television at restricted times. In countries where vulnerable groups and people with HIV are extremely marginalised, especially compared to San Francisco, great care must be taken to avoid increasing stigma and discrimination. The active involvement of people with HIV in planning and implementing such campaigns is therefore essential, as is the need to tailor messages to the diverse groups of people with HIV.

These campaigns depend upon people with HIV having access to mass media, telephones and the internet. Yet many people with HIV in developing countries are not literate and do not have access to these means of communication. Organisations should therefore undertake a careful feasibility assessment before implementing elements of this strategy.

Strategy 11: Training people with HIV as peer outreach workers

STRATEGY 11: TRAINING PEOPLE WITH HIV AS PEER OUTREACH WORKERS

Objective of Strategy 11:
To increase the visibility of people with HIV in order to reduce community-based stigma.

Description of Strategy 11:
Close contact with people with HIV as 'ambassadors of positive living' (Coutinho 2002) can help overcome fear, decrease discrimination, question stereotypes and myths, and enable people to recognise personal vulnerability to HIV.

A study in Thailand found that a tolerant attitude towards HIV/AIDS was significantly correlated to personal history of contact with people with HIV *(Takai et al. 1998)*. In this way, disclosure can be seen as a tool for combating stigma and discrimination *(David et al. 2002)*. It is also anticipated that people with HIV are effective in communicating HIV/STI prevention and sexual well-being messages to other people with HIV and those not infected.

Personal testimonies by 'positive speakers' have been found to be powerful vehicles of HIV/AIDS information, both for people with HIV and those not infected.

Smith and Katner (1995) studied the relative effects on American students of a role-play about HIV/AIDS, a question-and-answer session, and a talk by a people with HIV. Students in the people with HIV group perceived their activity to be the most worthwhile and interesting and the least embarrassing.

3.3 Community mobilisation

Strategy 11: Training people with HIV as peer outreach workers

Similar results were found in Australia where people with HIV from the Positive Speakers Bureau use personal story-telling as a health promotion strategy for people with HIV and with healthcare workers. Participants in HIV/AIDS awareness training reported people with HIV speakers as the most effective educational intervention for connecting theory of HIV to reality. Moreover, speakers themselves reported an increased sense of well-being related to the therapeutic function of sharing one's story and the sense of their ability to create positive changes in the lives of other people with HIV, and in community perception of HIV *(McKenna et al. 1997).*

Drama groups are another culturally appropriate way in which people with HIV can share their testimonies and promote positive behavioural change, as TASO drama groups in Uganda have done successfully. These have helped prevention become more of a community concern (Matovu et al. 2000; Coutinho 2002).

Evidence for the effectiveness of Strategy 11 in positive prevention:
Little, if any, research has been conducted on how strategies designed to increase the visibility of people with HIV in the community and improve attitudes towards people with HIV actually influence the behaviour (e.g. VCT uptake or safe sexual behaviour) of other people with HIV.

Issues for consideration when adapting Strategy 11:
The initiative to get involved in outreach education must come from people with HIV themselves.

People with HIV can take an active part in prevention work provided that they are given good training, supervision and support.

People with HIV must be counselled and allowed to make decisions about their own disclosure and visibility. It is also possible for people with HIV to be involved with outreach education with the use of pseudonyms to maintain anonymity (as Pinoy Plus in the Philippines has done; Alliance 2000).

Matching the gender, age, and sexuality of the speaker/outreach education worker to the characteristics of the targeted audience is likely to optimise the effectiveness of the interaction.

Strategy 12: Reinforcing Positive Prevention through home-based care

Involving asymptomatic people with HIV in communication and prevention efforts is important to show that sero-status cannot be determined by outward appearance.

Working with people with HIV as community resources can be cost-effective, although speakers should be remunerated adequately, financially or in kind (Horizons/Alliance 2002).

STRATEGY 12: REINFORCING POSITIVE PREVENTION THROUGH HOME–BASED CARE

Objective of Strategy 12:
To promote sexual health and HIV/STI prevention strategies with people with HIV and with the wider community.

Description of Strategy 12:
Home–based care services link with prevention in two ways. First, they provide opportunities to promote safer sex, to make referrals for STD diagnosis and treatment and for PMTCT services within HIV-affected households. Second, they also provide opportunities to reinforce prevention within the wider community, since the visibility of home-based care and support offers a powerful challenge to stigma and discrimination, encouraging community acceptance of and responses to HIV (Wilkinson et al. 2000).

Evidence for the effectiveness of Strategy 12 in positive prevention:
An evaluation of the Ministry of Health/Khana Home Care Programme for people with HIV in Cambodia found that 45% of people with HIV said that the home care teams had increased their comfort in sharing information about their HIV status with others. Moreover, 27% of people with HIV (including several SWs) said that they now use condoms as a result of their increased knowledge about HIV transmission. Many others were already using condoms or were no longer having sexual intercourse (Wilkinson et al. 2000).

The same evaluation in Cambodia identified that people with HIV experienced less discrimination as a result of the home care team's work, and village leaders reported that the community's knowledge about condom use and HIV had increased due to the visibility of the team.

Strategy 12: Reinforcing Positive Prevention through home-based care

Experience in Andhra Pradesh indicates that community-based care and support provided by SHADOWS, an AIDS service organisation, has led to increased people coming forward for VCT (Solomon et al. 2002).

More rigorous research is required to assess the extent to which community-based care and support strategies can reduce risk behaviours of positive people.

Issues for consideration when adapting Strategy 12:
Community-based leaders need to be involved from the start.

A participatory community assessment provides a good starting point from which to design interventions that maximise the prevention potential of home-based care.

Home-based care volunteers need careful selection and training in order to integrate care and support with HIV prevention, sexual well-being, community sensitisation and mobilisation.

Strategy 13: Addressing HIV-related gender-based violence in Positive Prevention

STRATEGY 13: ADDRESSING HIV-RELATED GENDER-BASED VIOLENCE IN POSITIVE PREVENTION

Objective of Strategy 13:
To change community norms and attitudes surrounding violence against women living with HIV.

Description of Strategy 13:
Fear of violence undermines positive prevention efforts by reducing women's willingness and ability to be tested for HIV, to share test results, to negotiate condom use and to comply with bottle-feeding infants or ARV regimens for PMTCT. Fear of violence also undermines positive prevention efforts in populations which already experience high levels of violence, such as SWs.

Community health promotion activities and mass media communication campaigns can be used to challenge harmful gender norms and HIV-related stigma.

healthcare providers and others need to address these issues during HIV counselling, particularly in relation to PN and disclosure. However, efforts to address HIV-related violence must move beyond the health facility into the community.

There appears to be a gap in the literature regarding community-level interventions that are aimed at women living with HIV, and working with men to reduce violence related to HIV sero-status. However, many communication campaigns and community health promotion activities have addressed violence against women more generally.

One effective example is Stepping Stones, a curriculum for sexual health and HIV prevention. This uses a problem-posing approach to encourage reflection on complex issues such as trust, risk, the meaning of love, learning to say 'no'. A South African adaptation of the curriculum added a module specifically to address abuse and sexual coercion in relationships, although this did not focus on issues faced specifically by people with HIV *(Population Reports 1999)*.

Strategy 13: Addressing HIV-related gender-based violence in Positive Prevention

Evidence for the effectiveness of Strategy 13 in positive prevention:
There appears to be a distinct lack of evidence regarding the effectiveness of community health promotion interventions such as Stepping Stones, and mass media campaigns in reducing violence towards women living with HIV. Consequently, there is no evidence to indicate the relationship between community-level violence reduction strategies and their ability to reduce risk behaviours and STI/HIV transmission.

There is an urgent need to pilot and evaluate community-based interventions that tackle gender-based violence towards women living with HIV, particularly in low-prevalence contexts.

Issues for consideration when adapting Strategy 13:
Changing community norms alone will not eliminate violence. Strong co-ordination is needed between health providers, community health promoters, community leaders, law enforcement agencies, women's groups and people with HIV support groups to tackle gender-based violence.

Institutions in the community can best respond if they are trained and organised to do so.

3.4 ADVOCACY, POLICY CHANGE AND COMMUNITY AWARENESS

The following strategies operate at the structural level to tackle the policy and legal contexts that help shape the world in which people with HIV live, and which either facilitate or impede an individual's ability to modify or maintain safe behaviours.

Examples of structural factors that hinder prevention efforts among people with HIV include public policies that violate human rights and encourage discrimination of people with HIV. This includes policies promoting name-based HIV reporting and mandatory PN, which have a disproportionately negative impact on women.

Other structural factors include stigma and discrimination, lack of informed consent and confidentiality laws for HIV testing. Policy decisions about resource allocation for positive prevention programmes, tariffs or advertising bans on condoms, criminalisation of non-disclosure and restrictions on content of school-based curriculum on sexuality can all become structural barriers to positive prevention (Shriver et al. 2000).

At a 'super-structural' level, factors such as gender inequalities, poverty, migration and homophobia are also determinants of vulnerability to HIV infection and its consequences. These require very broad-based interventions that are beyond the scope of this document.

It should be noted that the evidence base regarding structural interventions for HIV prevention is very recent, especially in relation to people with HIV, and there is little published evidence demonstrating causal relationships between changes in structural conditions, risk reduction behaviours and HIV outcomes. New methodologies will be required to assess strategies that create an environment conducive to effective positive prevention strategies.

STRATEGY 14: INVOLVING PEOPLE WITH HIV IN DECISION-MAKING FOR POSITIVE PREVENTION

Objective of Strategy 14:
To promote the meaningful involvement of people with HIV in positive prevention through work with NGOs, government ministries and other organisations.

3.4 Advocacy, policy change and community awareness

Strategy 14: Involving people with HIV in decision-making for Positive Prevention

Greater Involvement of people with HIV

"When decisions are being made, we want to be part of the process right from the start. We want to be there because this is about our lives and the lives of those we love. We want to be there because we know what our needs are better than anyone else. We want to be there because we have a substantial contribution to bring. An era has come to an end: we want to do more than just 'giving the epidemic a human face and voice' because we are not just faces to showcase and voices to hear. We are people; no more but no less! We are resources! This is our commitment, this is our work, we can do it, we will do it.

Salvatore Niyonzima, UNAIDS, quoted in 10th International Conference for People Living with HIV/AIDS Post Conference Report: Celebrating Our Lives, GNP+ (2001)"

Description of Strategy 14:
Promoting the meaningful involvement of people with HIV in the response to HIV is really a principle rather than a strategy as such, and cuts across the whole framework of interventions.

The Alliance-led Horizons study, in its analysis of types of and pathways to involvement, suggested that there may be a continuum of involvement, which can also be applied to positive prevention *(Horizons/Alliance 2002).*

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

The study notes that this continuum is both an individual and an organisational process and does not necessarily have to take place in the same NGO. The experience, training and skills of individual positive people will also determine at which stage they join the continuum.

3.4 Advocacy, policy change and community awareness

Strategy 14: Involving people with HIV in decision-making for Positive Prevention

UNAIDS (Sept. 1999) has developed a 'pyramid of involvement' by people with HIV to show how the GIPA principle (Greater involvement of People living with or affected by HIV/AIDS) is applied at all levels, from being target audiences for activities aimed at people with HIV, to contributors, speakers, implementers, experts and ultimately decision-makers. The involvement of people with HIV is key in helping to realise an approach to HIV/AIDS that follows the prevention-care continuum.

AIDS NGOs are increasingly employing people who are open about their positive HIV status as staff members and in governance. There are currently fewer people with HIV openly working as staff in government and in the private sector, but this trend can and should be encouraged: for instance, people with HIV in health, education and defence ministries, in personnel departments and providing staff training. An organisation may have to positively discriminate in favour of recruiting a person with HIV, and extra training may need to be given to develop their skills. The availability of professional people with HIV willing to disclose their status to work with an NGO may be limited in lower prevalence countries.

Skills–building of people with HIV required for meaningful involvement in decision-making and policy formulation can include:

- personal empowerment
- communication and presentation skills
- HIV/AIDS technical knowledge
- organisational development skills
- legal aspects of HIV/AIDS
- skills for organising and conducting policy dialogue
- leadership
- political commitment monitoring
- human rights observers.

Preparing organisations for meaningful involvement of people with HIV in the response. The orientation of organisations is equally important to prepare their readiness for people with HIV involvement (GNP+ 2001; UNAIDS 1999). Beyond people with HIV as clients, many organisations can see a benefit in supporting the involvement of people with HIV in the response. They understand that the response will be more effective when PLHA are part of decision-making and when they have a strong voice in advocacy.

3.4 Advocacy, policy change and community awareness

Strategy 14: Involving people with HIV in decision-making for Positive Prevention

Organisations need to create a working environment that is conducive to the involvement of people with HIV. This includes having the right organisational climate, attitudes, budget levels and policies to support people with HIV to work effectively at all levels within the organisation.

Similarly, donors, government bodies and other organisations need to understand the importance of PLHA playing key roles in the response, and themselves be prepared and motivated to support this involvement.

> Based on the findings and recommendations of the Horizons study on the involvement of people with HIV in community-based prevention, care and support programmes, the Alliance and its partners are developing a set of tools to help organisations prepare for scaling-up and institutionalising the meaningful involvement of positive people in the response to the epidemic. These will be finalised and available in 2004.

Evidence for the effectiveness of Strategy 14 in positive prevention:
There is general consensus that prevention efforts among people with HIV and those not infected in low HIV prevalence countries are far more effective when the communities who are most affected are involved (FHI/UNAIDS 2001). The vital role of the involvement of people with HIV in stigma reduction is a key element of prevention efforts.

Issues for consideration when adapting Strategy 14:
Involvement in the response does not mean necessarily disclosing one's sero-status. People with HIV have the right to choose to be involved without making their sero-status public or to choose the spheres of visibility they are ready for. Precautions are needed to protect people who do choose to disclose their positive sero-status, and training is needed to prepare people for visibility.

The risk of burnout of people with HIV involved in programmes and policy-making is high. There is a real need to recognise the increased likelihood that people with HIV will fall sick or die, and to plan openly for sustainability of initiatives that involve people with HIV (UNAIDS 1999; Horizons/Alliance 2002).

Strategy 15: Advocacy for Positive Prevention

It cannot automatically be assumed that someone with HIV will want to become part of the response. Many people choose this path thinking there are few other options for people with HIV. All other options should be explored thoroughly with people with HIV before they make a commitment to becoming involved.

STRATEGY 15: ADVOCACY FOR POSITIVE PREVENTION

Objective of Strategy 15:
To create a more supportive legal and policy environment for positive prevention strategies through advocacy and the involvement of people with HIV in policy making.

Description of Strategy 15:
Prevention starts with reducing stigma against people with HIV or affected by HIV/AIDS (GNP+ 2001).

Building the capacity of positive groups, CBOs, NGOs and networks to confront stigma and discrimination through advocacy and awareness raising is an empowering approach.

Examples of such groups include:

Positive Life Network, India: a coalition of individuals and institutions of people with HIV and people affected by HIV/AIDS seeking to mainstream care issues in order to increase the effectiveness of prevention strategies. It aims to provide a safe platform for people with HIV to network, with no threats of disclosing sero-status *(Mishara et al. 1998).*

Asia Pacific Network of people with HIV (APN+): an advocacy organisation that started in 1994 when 42 people with HIV from eight countries in the Asia Pacific region met in Malaysia. They agreed to lobby for the betterment of people with HIV in the region and to work against stigma and discrimination. APN+ now covers 10 countries *(UNAIDS 1999).*

Cambodian people with HIV Network (CPN+): a network for people with HIV support groups has recently emerged, and seeks to take part actively in policy and decision-making at the national and local level by linking with government and civil society *(Chhim 2002).*

3.4 Advocacy, policy change and community awareness

Strategy 15: Advocacy for Positive Prevention

An example from Mexico illustrates some of the potential activities that can form part of an advocacy campaign. In response to a series of discriminatory statements about people with HIV by the Yucatan State Commissioner on Human Rights, the Multisectoral Citizens' Group (MCG) undertook a range of advocacy activities over the next ten months. These included:

- letters to high-ranking authorities and elected officials
- press conferences with NGOs and a letter of support to denounce the Commissioners' statement and the overall environment of discrimination against people with HIV
- filing formal complaints to the National Commission on Human Rights (NCHR), protesting at discriminatory practices in the state and alleging violation of people with HIV's rights at a hospital where people with HIV were refused appropriate medical attention and subsequently died
- consistent media pressure
- presenting proposals at a consultative forum with the state legislature to reform the law that created the State Commission on Human Rights
- securing the participation of high-ranking state officials in the AIDS Day Walk *(POLICY Project 2002).*

People with HIV from such organisations can also be represented on national and international HIV forums to participate in strategic planning, resource mobilisation and policy formulation.

Evidence for the effectiveness of Strategy 15 in positive prevention:
As a result of the MCG campaign, the NCHR issued a formal recommendation to the state of Yucatan. Further, one NGO member of the MCG filed formal complaints to the NCHR on its own behalf regarding alleged ill-treatment of people with HIV prisoners. The state legislature voted to reform the State Law on Human Rights (POLICY Project 2002).

Whilst these outcomes demonstrate improvements in the legal framework for people with HIV, there are no attempts to measure the impact of these changes on people with HIV's ability to reduce risk behaviours to prevent onward HIV transmission. New evaluation methodologies are required.

Strategy 16: Legal reviews and legislative reform

Issues for consideration when adapting Strategy 15:
Experience suggests that lobbying bureaucrats effectively requires: building partnerships and alliances with the interest of people with HIV at the heart of the strategy; knowing the issues from the governments' perspective; targeting advocacy efforts to decision-makers and understanding their motives (GNP+ 2001).

STRATEGY 16: LEGAL REVIEWS AND LEGISLATIVE REFORM

Objective of Strategy 16:
To protect and promote the human rights of people with HIV and contribute to destigmatisation, in order to facilitate positive prevention strategies.

Description of Strategy 16:
This strategy aims to strengthen the human rights framework for people with HIV. Legal reform can also assist in destigmatising HIV and AIDS.

An analysis of laws in nine Latin American countries (including Ecuador, Argentina, Honduras) found that: some policies hinder the development of laws to ensure human rights of people with HIV and facilitate their access to resources; other policies foster the stigmatisation of people with HIV. Policies which foster an 'us against them' attitude between people with HIV and those not infected, have detrimental effects on the prevention of the epidemic and access to care and support *(Varas-Diaz 2000).*

A practical human rights approach involves:

- conducting a legal analysis to understand the sources of discrimination against people with HIV and vulnerable groups in human rights, legal and regulatory frameworks on HIV and AIDS
- identifying national norms/policies and comparing them with International Guidelines on HIV/AIDS and Human Rights to find discrepancies
- identifying laws that should be modified, deleted or added; sharing legal review and discussion findings with people with HIV and NGO networks to strengthen their advocacy efforts
- holding a policy dialogue roundtable with policy-makers and NGO representatives to engage them in working together for policy change.

Strategy 16: Legal reviews and legislative reform

> Tools to support the legal analysis include: *UNAIDS Protocol for the Identification of Discrimination Against People Living with HIV*, and Futures' *HIV/AIDS Legislation Score: an indicator for discrimination provisions in national or sub national HIV/AIDS legislation* (2001). This approach is being implemented in Ethiopia, Egypt, Peru and Ukraine *(POLICY Human Rights Working Group 2002).*

Evidence for the effectiveness of Strategy 16 in positive prevention:
The outcomes of these legal reviews have not yet been evaluated in terms of changed laws and policies, let alone in terms of their impact on facilitating positive prevention strategies.

However, there is consensus that documenting abuses within a human rights framework is essential to identifying government responsibility and means of redress for people with HIV. As such, rights analysis is crucial for effective public policy (Kaplan et al. 2002).

The next step is to assess the extent to which people with HIV are aware of their human rights and legal protections and perceive that this protection is real. In turn, these perceptions need to be linked to prevention needs in order to assess the extent to which such awareness of laws facilitates positive prevention (Shriver et al. 2000).

Issues for consideration when adapting Strategy 16:
In countries where the overall human rights framework is already very weak, the human rights of people with HIV are likely to be even less well protected and upheld than other citizens. In these contexts, even more care must be taken to ensure that advocacy and legal review strategies do not exacerbate discrimination against people with HIV and vulnerable populations.

CBOs/NGOs will need to collaborate with advocacy organisations or lawyer's associations in order to have the skills necessary to implement this kind of strategy.

The participation of trained people with HIV is a key element in creating effective and non-discriminatory AIDS-related legislation (Pascal et al. 2000, Chile).

Strategy 17: Advocacy for access to treatment

Developing communication strategies to increase people with HIV's awareness of their rights, and establishing mechanisms to seek redress (e.g. Costa Rican Ombudsman Office (Valerio 2002), are needed to complement changes in the legal framework.

STRATEGY 17: ADVOCACY FOR ACCESS TO TREATMENT

Objective of Strategy 17:

To influence policies for increasing the availability of ART to people with HIV in order to reduce stigma associated with HIV/AIDS and to facilitate prevention efforts.

Description of Strategy 17:

The possibility of long-term clinical management of HIV/AIDS through ART is beginning to shift people's perceptions away from seeing HIV/AIDS as a fatal disease with no hope, towards a condition that can be lived with positively.

It is expected that policies to increase access to ART can facilitate positive prevention efforts in two related ways. First, by reducing stigma and discrimination associated with HIV and AIDS, and so creating an environment in which people with HIV are more likely to come forward for testing, prevention and care. Second, with the hope of receiving treatment providing stronger incentives for people with HIV to come forward for VCT, to disclose their status to partners and to receive prevention counselling.

There is increasing experience of **advocacy by people with HIV** being an effective strategy in influencing policies to increase access to ART.

Strategy 17: Advocacy for access to treatment

Advocacy movements led by positive people have been instrumental in generating political commitment in Thailand and Brazil in particular.

Countrywide policies have been adopted in Brazil to guarantee that ARVs will be provided for anyone with HIV who needs them, and to allocate considerable resources to the manufacture and importation of generic versions of patent-protected drugs. Pressure is being maintained to ensure that the Brazilian government continues to provide ARVs free of charge *(Horizons 2002)*.

In Thailand, activists led by the Thai Network of people with HIV (TNP+), the International Gay and Lesbian Human Rights Commission and the Thai NGO Coalition on AIDS mobilised sustained efforts, including demonstrations and letters, to demand that the Thai government treat people with HIV equally by including ARVs under the universal healthcare plan and increases the budget *(Suwannawong 2002; PWHA-NET 1 Dec. 2001)*. This secured an immediate positive commitment from the government.

In Ecuador, FEDAEPS is struggling to put ART on the national agenda, recognising the need for a holistic proposal developed with other key players *(Leon 2002)*.

Litigation strategies have also been used to influence policy on access to treatment for HIV/AIDS, as the high-profile case of South Africa demonstrates.

Strategy 17: Advocacy for access to treatment

The South Africa Treatment Action Campaign (TAC) campaigns for the development, adoption and implementation of a comprehensive national treatment plan for people with HIV and also works towards the prevention and elimination of new HIV infections. TAC was very successful in securing a court judgement ordering the Ministry of Health to provide nevirapine where public health facilities have the capacity to do so and to roll out a comprehensive national PMTCT programme. In addition, the litigation process also captured the attention of people with HIV, the general public, health providers, media and political leaders. This process shows that by framing political and moral demands for ART in the language of human rights and constitutional obligations, TAC sought to use the law without necessarily having to litigate. TAC continues to develop other litigation strategies to gain access to treatment for HIV/AIDS *(Berger 2002)*.

Evidence for the effectiveness of Strategy 17 in positive prevention:
One example of the prevention-treatment-care continuum in action comes from a small study in a resource-poor community of Haiti. Directly observed ART was introduced to 60 people with HIV. Authors observed that ART reinvigorated flagging prevention efforts by lessening AIDS-related stigma in the community. This resulted in increased demand for HIV testing and more opportunities for counselling (Farmer et al. 2001).

Further research is needed to assess whether increased availability of ART does reduce stigma surrounding HIV and AIDS and thereby creates a more supportive environment for prevention activities with people with HIV (Horizons 2002).

Issues for consideration when adapting Strategy 17:
Building an advocacy movement driven by positive people presumes the existent of a cohesive community of activists.

Developing advocacy or litigation strategies with other allies in civil society, business, government and international community is very powerful. For example, TAC joined forces with the Congress of South African Trade Unions who brought to the fore the experiences of people with HIV.

Strategy 17: Advocacy for access to treatment

Maintaining independence is crucial for advocacy groups. This requires ensuring that decisions to support or oppose government and private-sector policies are driven by identifying and challenging obstacles to treatment access, rather than any political motivations.

See also experiences of advocacy compiled by the Alliance in *Improving Access to HIV/AIDS-related Treatment* (2002).

4.1 Useful websites

This section gives website addresses which are useful for accessing further information about positive prevention. This is followed by a list of references made in the text. Where possible, direct web links are included with the references.

4.1 USEFUL WEBSITES

AIDS Education Global Information Service
www.aegis.com
AIDSmap: maintained by NAM Publications, BHIVA and International HIV/AIDS Alliance
www.aidsmap.com
Center for AIDS Prevention Studies, AIDS Research Institute, University of California
www.caps.ucsf.edu/publications/
Center for Disease Control and Prevention, USA
www.cdc.gov
ELDIS library, Institute of Development Studies
www.eldis.org/hivaids/index.htm
Family Health International IMPACT project
www.fhi.org/en/aids/impact/iohiv/ioh11/index.html
Futures Group POLICY project
www.policyproject.com
Global Network of People living with HIV/AIDS
www.gnpplus.net
HIV Stops With Me Campaign
www.hivstopswithme.com
Horizons Programme, Population Council
www.popcouncil.org/horizons/horizons.html
Institute of Development Studies, University of Sussex – insights newsletter
www.id21.org/insights/
International HIV/AIDS Alliance
www.aidsalliance.org
National Association of People with AIDS (USA)
www.napwa.org
National AIDS Trust (UK)
www.nat.org.uk
National HIV Prevention Information Service (UK)
www.hda-online.org.uk/nhpis
PWHA discussion list (pwha-net@lists.health.dev.net)
http://archives.hst.org.za/pwha.net/

Terrence Higgins Trust
www.tht.org.uk
The Body
www.thebody.com
UNAIDS
www.unaids.org
University of California, San Francisco AIDS Health Project
www.ucsf-ahp.org
University of California, San Francisco AIDS Research Institute
http://ari.ucsf.edu

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