People living with HIV, like those who are HIV negative, play an essential role in preventing new HIV infections. Key approaches for prevention for and by people living with HIV include individual health promotion, access to HIV and sexual and reproductive health services, community participation, advocacy and policy change.
The patterns in this publication are based on traditional kolam – floor drawings made by women in the Tamil Nadu region of South India. Made from one continuous line the patterns mark domestic entrances and are thought to invite in wealth and prosperity.
# Introduction

**Who is this guide for?**

**What is the aim of this guide?**

**Who developed this guide?**

**How is this guide structured?**

**Acronyms**

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# Appendix

**Useful resources related to positive prevention**

42
Introduction

Who is this guide for?

This guide on positive prevention1 was developed to assist people living with HIV, service providers and policy makers to understand, promote and implement appropriate rights-based strategies for addressing the prevention needs of people living with HIV. The guide includes sections which focus on action points and provides useful information on key issues to consider when developing prevention programmes for people living with HIV.

The main audiences of this guide includes networks and organizations of people living with HIV, civil society organizations, health providers, programme managers, donors, United Nations agencies and government officials.

What is the aim of this guide?

The information included in this guide intends to promote dialogue and discussion among people living with HIV, service providers, programme managers and policy makers on the key principles and issues to consider when developing programmes and strategies to address the prevention needs of HIV positive people. While there is wider recognition on the importance of linking prevention, treatment, care and support for people living with HIV, consensus has not been reached on the key elements of positive prevention. This guide intends to fill this gap by providing some ideas and concepts that can help to better understand the ingredients and operational principles to be considered when designing and implementing positive prevention programmes.

Who developed this guide?

This guide was developed by the Family Planning Association of India (FPA India), and the Indian Network of People living with HIV (INP+) with support from the International Planned Parenthood Federation (IPPF) Central Office and South Asia Regional Office as part of a three year project implemented by Madurai Branch of FPA India. Working in the Madurai district, FPA India has helped to improve the quality of life of people living with HIV by providing comprehensive sexual and reproductive health and HIV information and services. They identified the necessity to address the unmet prevention needs of people living with HIV as a critical gap in this comprehensive approach. An independent consultant from the Indian Network of People living with HIV (INP+) was contracted to develop the initial draft in consultation with the local community of people living with HIV and staff and health providers from FPA India.

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1. It is acknowledged that ‘positive prevention’ is not a universally accepted term. The use of the term in this guide is based on a set of principles agreed by FPA India, INP+ and IPPF during the implementation of this project. At its core, it aims to address the key prevention needs of people living with HIV.
How is this guide structured?

The guide is structured into three sections.

The **first section** presents an introduction to positive prevention and the key principles underpinning this concept. This section also highlights the main reasons why we need to develop prevention programmes for people living with HIV.

The **second section** highlights the three pillars of positive prevention that should be considered when developing comprehensive programmes for positive prevention:

1. Protecting your sexual and reproductive health – and avoiding other sexually transmitted infections (STIs)
2. Delaying HIV disease progression
3. Promoting shared responsibility to protect your sexual health and reduce the risk of HIV transmission.

Each of these themes are then explored by using the following key questions:

- What does it mean for people living with HIV?
- Why is it important?
- What can you do?
  - A list of 10 priority actions for people living with HIV
  - A list of 10 priority actions for service providers
  - A list of 3 priority actions for advocates and policy makers
- How do we know this works?
- What are some of the issues to consider?

The **last section**, At a glance, presents an overarching strategy to respond to the prevention needs of people living with HIV, as well as individual strategies for specific groups, such as men and boys, men who have sex with other men, people who use drugs, sex workers, transgendered people, women and girls, and young people.

While this guide offers a menu of key actions across the three pillars of positive prevention, it was not designed to be read from cover to cover. Each section presents relevant information and guidance for a variety of stakeholders. At times a number of salient points are emphasised examining the same topic from different perspectives. Readers are invited to select and use the different sections according to their own areas of interest or work.
## Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>ATS</td>
<td>Amphetamine-type stimulants</td>
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<tr>
<td>CHW</td>
<td>Community health worker</td>
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<tr>
<td>FHOK</td>
<td>Family Health Association of Kenya</td>
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<tr>
<td>FP</td>
<td>Family planning</td>
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<tr>
<td>FPA India</td>
<td>Family Planning Association of India</td>
</tr>
<tr>
<td>GIPA</td>
<td>Greater involvement of people living with HIV</td>
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<tr>
<td>GNP+</td>
<td>Global Network of People Living with HIV</td>
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<tr>
<td>HBV</td>
<td>Hepatitis B virus</td>
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<tr>
<td>HCV</td>
<td>Hepatitis C virus</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>HPV</td>
<td>Human papilloma virus</td>
</tr>
<tr>
<td>HSV</td>
<td>Herpes simplex virus</td>
</tr>
<tr>
<td>IEC</td>
<td>Information education and communication</td>
</tr>
<tr>
<td>INP+</td>
<td>Indian Network for People living with HIV/AIDS</td>
</tr>
<tr>
<td>IUD</td>
<td>Intra-uterine device</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
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<tr>
<td>OI</td>
<td>Opportunistic infections</td>
</tr>
<tr>
<td>OST</td>
<td>Opioid substitution therapy</td>
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<tr>
<td>PLHIV</td>
<td>People living with HIV</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission</td>
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<tr>
<td>SRH</td>
<td>Sexual and reproductive health</td>
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<tr>
<td>STI</td>
<td>Sexually transmitted infections</td>
</tr>
<tr>
<td>SW</td>
<td>Sex worker</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>VCT</td>
<td>Voluntary counseling and testing</td>
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<tr>
<td>VCTC</td>
<td>Voluntary counseling and testing centre</td>
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In this section

- Setting the scene: Making prevention fit for purpose
- What is positive prevention?
- What are the benefits of positive prevention?
- HIV prevention in context
- Why should we promote positive prevention?
Setting the scene: Making prevention fit for purpose

Since HIV made its debut on the international stage almost 30 years ago, much has been learnt about prevention. Knowledge about HIV transmission, safer sex practices, pre- and post-exposure prophylaxis, male circumcision, the role of key interventions to prevent HIV transmission from mother-to-child, harm reduction initiatives for people who use drugs and rights-based approaches have dramatically altered the prevention landscape.

‘Traditional’ prevention programmes have however mostly targeted those people who are HIV negative and have promoted a wide range of behaviour change strategies. While this is crucial, they have largely ignored both the needs and important role of people who are HIV-positive. The assumption that knowledge of HIV status alone will ensure sustained safer sex practice is being increasingly called into question. The key to sustained behaviour change continues to remain elusive. With the increasing availability and uptake of antiretroviral therapy (ART) becoming a reality and the potential for ART to act as an effective means of HIV prevention, the global HIV prevention agenda needs to keep pace with the ever-changing demands of the day by responding to the specific prevention needs of people living with HIV. The increasing number of sero-discordant and concordant relationships1 carries in its wake the importance of responding to the sexual and reproductive health needs and fertility choices of a diverse group of people.

A number of approaches have been used to respond to the prevention needs of HIV-positive people but most of them have focused solely on the need to reduce HIV transmission and contain the epidemic among those who know their HIV status. These types of interventions have received great resistance from the HIV positive community who have called for a more holistic approach to health and well-being. The newly created Positive Health Dignity and Prevention movement2 led by the Global Network of People Living with HIV (GNP+) has highlighted the need to promote a new approach that goes beyond health related services and include other interventions to deal with issues of disclosure, sexuality, drug use and laws, within a human rights approach. While the options to be included in this comprehensive movement are many, it is important to ensure that we are all able to better articulate and respond to the specific prevention needs of people living with HIV.

Prevention has always been and should remain an intensely personal issue. Legislating behaviour change for people living with HIV will not only decrease the imperative to know one’s HIV status but will also increase the gender related divisions of this epidemic. Therefore rational arguments based on human rights need to be made to support people living with HIV to make their own prevention decisions. Hand in hand with this, national HIV prevention programmes need to be implemented and scaled up to ensure the prevention agenda is fit for purpose.

1. Sero-discordant relationship is used when one member of a couple is HIV-positive and the other is HIV negative, while concordant relationship is used when both members of a couple are HIV-positive.
What is positive prevention?

Positive prevention can be defined as a set of strategies that help people living with HIV to live longer and healthier lives. It encompasses a set of core elements that help people living with HIV to:

- Protect their sexual and reproductive health – and avoid other sexually transmitted infections (STIs);
- Delay HIV disease progression; and
- Promote shared responsibility to protect their sexual health and reduce the risk of HIV transmission.

People living with HIV, like those who are HIV negative, play an essential role in preventing new HIV infections. Key approaches for prevention for and by people living with HIV include individual health promotion, access to HIV and sexual and reproductive health services, community participation, advocacy and policy change.

The following four guiding principles influence the content and approach to positive prevention:

1. Promotion of human rights
   Protection of the rights of people living with HIV is of paramount importance. These include their right to privacy, confidentiality, informed consent and voluntary disclosure. It is also important to ensure a supportive and enabling environment that does not undermine prevention efforts. The use of prevention strategies that are based on coercion and criminalization will continue to fuel stigma and discrimination, deterring people from accessing services.

2. Involvement of people living with HIV
   Application of the Greater Involvement of People living with HIV and AIDS (GIPA) principle will ensure the active involvement of HIV-positive people in decision making processes that affect their lives. The active involvement of people living with HIV in identifying their own prevention needs is key to the success of positive prevention interventions.

3. Shared ownership and responsibility
   The responsibility for reducing the transmission of HIV rests with everyone and not only people living with HIV. Safer and responsible sexual behaviour is the responsibility of all partners, irrespective of their HIV status. It also lifts the burden from people who are aware of their status and could improve communication and equality within relationships.

4. Recognition of diversity
   Positive people have a variety of needs which are also influenced by gender, age, ethnicity, sexual orientation, drug use and risk profile, length of time living with HIV and whether one is on treatment or not. Positive prevention strategies need to be tailored to respond to these diverse needs.

What are the benefits of positive prevention?

To date, most HIV prevention campaigns and strategies have focused their attention on people who are not living with HIV and very little attention has been placed on promoting prevention strategies to support people who are already living with HIV. An essential element of this approach is to ensure that people living with HIV live longer and healthier lives. This, in turn, will contribute to the well-being of their partners, families and communities.

Of the estimated 33 million people living with HIV, 95% live in developing countries; it is further estimated that 9.5 million people were in need of treatment but only 42% were receiving it at the end of 2008. Increased access to antiretroviral therapy (ART) has brought hope for millions of people living with HIV but it has also presented new challenges in the response to HIV - including the emerging need to ensure that existing programmes are scaled up to reach more people and funding is sustained to ensure the continuation of these programmes. While some people need to access ART immediately; others can live for many years without requiring treatment. Positive prevention programmes need to address the real circumstances of people’s lives.

The benefits of responding to the prevention needs of people living with HIV are well known:

- It can contribute to the full enjoyment of sexual and reproductive health and rights;
- It can promote new ways to live in sero-discordant or concordant relationships;
- It can avert unnecessary illnesses and ensure timely access to treatment, care and support;
- It can promote adherence to ART;
- It can contribute to opening up a frank dialogue among health providers, among people living with HIV, community members, parliamentarians and other stakeholders about the need to promote an environment free from stigma and discrimination;
- It can help HIV-positive people to be empowered to make decisions about their lives without the burden of feeling guilt or shame as a result of their HIV status.

The success of ART programmes is also bringing new opportunities for prevention. A strong body of evidence is emerging showing the potential impacts of treatment on prevention. By reducing viral load through effective ART the level of infectiousness is also reduced and therefore the risk of HIV transmission is lowered – making ART potentially the best prevention strategy currently available. What this means for people living with HIV is that access to effective treatment is important not just for their own health but also in reducing the risk of HIV transmission to their sexual partners.

Integrating positive prevention into existing prevention programmes is also essential to ensure that positive prevention does not stand alone. Establishing parallel or vertical prevention programmes for HIV-positive people can increase stigma and discrimination and may be received with suspicion by people living with suspicion.


HIV prevention in context

A comprehensive approach to prevention should consider the context of people’s lives – particularly in terms of age, sex, the time since they were diagnosed with HIV and, when or if treatment started. These factors will have different implications for prevention. The table below illustrates some of the key questions people living with HIV may have in relation to their prevention needs. The questions below do not attempt to cover all the issues faced by people living with HIV or simplify the complexity of our identities but to illustrate the dilemmas people confront in their real lives. Some of these illustrative questions could apply to everyone while other questions are more relevant to specific groups:

### Key questions people living with HIV may have in relation to their prevention needs

<table>
<thead>
<tr>
<th>Category</th>
<th>Questions</th>
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| **Men and boys**          | - Where can I access treatment and services for sexually transmitted infections?  
                            | - Do I have to disclose my status to all my previous sexual partners?  
                            | - Do I have to use condoms with my regular partners?                   |
| **Men who have sex with men** | - Where can I go to get support or counselling around issues related to my sexuality and the stigma I experience as a man living with HIV?  
                            | - If I practice unsafe anal sex with another HIV-positive man, will I be at risk of re-infection with a different HIV strain?  
                            | - How can I disclose my sexual practices when homosexuality is considered a criminal act in my country? |
| **People who inject drugs** | - If I am currently using heroin, do I need to start methadone therapy before starting ART?  
                            | - What should I tell my sexual partner about my HIV or hepatitis C status?  
                            | - Where can I go to get health services that do not discriminate against people who use drugs? |
| **Sex workers**           | - Will I be excluded from the workplace if I disclose my status to my fellow sex workers or the owner of the place where I work?  
                            | - While I may find it easier to negotiate condom use with my clients, how can I discuss condom use with my regular partner who does not want to use condoms?  
                            | - Does the law require me to disclose my status to my clients if I always use condoms? |
| **Transgendered people**  | - Are there any contraindications between the hormones I am taking and ART?  
                            | - Where can I access non discriminatory services?  
                            | - Who can I speak to about sexual violence and abuse? |
| **Women and girls**       | - How can I discuss condom use with my regular partner/spouse?  
                            | - How can I get support in talking to my partner about my sexual and reproductive health needs when I am unsure of how my partner might react?  
                            | - If my partner is negative/positive and we want to have children, what do we need to do to avoid HIV transmission during conception and pregnancy? |
| **Young people**          | - Should I only get involved with someone who is also HIV-positive?  
                            | - When and how should I disclose my status to a potentially new sexual partner?  
                            | - Can and should I have children? |
Why should we promote positive prevention?

Because....

- Positive prevention is largely being ignored by donors, governments, health care providers and programme managers. Most efforts and resources have been focused on preventing new HIV infections.
- Often people living with HIV do not necessarily recognise their prevention needs, as treatment has been seen as more important.
- Positive prevention is an effective and practical way to promote linkages between HIV and sexual and reproductive health issues.
- Most interventions focus on preventing onward transmission. There are very few documented examples of interventions that tried to move beyond reducing individual risk by offering a holistic approach to prevention, framed on a rights based approach.
- At a policy level there is a clash between policies and laws. The tension between promoting individual rights and public health benefits can have a negative effect on prevention efforts. For example, the fact that criminalization of onward transmission is increasingly a reality in many countries, has hindered the effectiveness of many prevention programmes.
- Consensus has started to emerge on the need to promote a global agenda for Positive Health Dignity and Prevention which includes addressing the prevention needs of people living with HIV as well as considering broader aspects such as the promotion of a supportive and protective legal environment free from stigma and discrimination.
- People need practical guidelines and many programme managers, service providers and policy makers don’t know how positive prevention fits into their work, even though many may already be implementing certain elements of positive prevention in existing programmes.
- It works! There is emerging evidence that prevention strategies to support people living with HIV to protect their health and well-being, do work. More research, however, is needed to assess the benefits of implementing a holistic package for positive prevention that is tailored to the diversity of needs of people living with HIV and which measures health outcomes as well as overall well-being.

Section 2

In this section

- Protecting your sexual and reproductive health and avoiding other sexually transmitted infections (STIs)
- Delaying HIV disease progression
- Promoting shared responsibility to protect your sexual health and reduce the risk of HIV transmission
1. Protecting your sexual and reproductive health and avoiding other sexually transmitted infections

What does it mean for people living with HIV?

People living with HIV have the right to live enjoyable and fulfilling sexual and reproductive health lives. Most people living with HIV will remain sexually active and health-care providers should respect their right to do so, supporting them and their partners in protecting their sexual and reproductive health. Sexual life and pleasure does not stop with an HIV positive diagnosis. While some positive people may decide not to continue sexual activities after their initial HIV diagnosis, others continue to have sex. Effective ART has brought hope to many people living with HIV and has opened up the desire to have children for some HIV-positive people. People living with HIV are a diverse group with very specific needs. Whether they are women, girls, men, boys, men who have sex with men, transgendered people, sex workers, people who use drugs or young people, they all have the right to access effective sexual and reproductive health services tailored to their specific needs.

Why is it important?

People living with HIV need to access sexual and reproductive health services and receive appropriate information in order to make informed decisions regarding their sexuality, sexual health and reproduction. This includes, for example, practicing safer sex; avoiding other sexually transmitted infections (STIs); reducing the chance of unintended pregnancies or planning a safe conception and healthy pregnancy if they want to have children (see box 1 for a list of key sexual and reproductive health services). It is vital that if positive people are going to protect and improve their sexual and reproductive health they have equitable access to these services. Treatment, care and support services for people living with HIV should also be integrated with these sexual and reproductive health services, through cross referrals and integrated services in clinics, so as to provide holistic care. Health-care providers need to recognize and address family planning and reproductive health issues as part of comprehensive HIV care and prevention services.

Many health providers find it difficult to discuss sexual health issues with their clients and sexual history taking is not always done appropriately. This can be a critical barrier for addressing the sexual health needs of people living with HIV, particularly as HIV has already had a real impact in the way people continue to enjoy their sexuality.

Box 1

Key sexual and reproductive health services

- Sexuality education
- Sexual health counselling
- Dealing with disclosure
- Condom promotion
- Diagnosis and treatment of STIs
- Screening for reproductive tract infections and cancers
- Access to family planning methods
- Access to abortion services and management of complications from unsafe abortions
- Safe conception counselling
- Access to services to prevent mother-to-child transmission.
- Counselling for breastfeeding and infant feeding
- Attended delivery
- Prevention and management of gender-based violence

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7. Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV. A Guidance Package. 2009. Global Network of People Living with HIV. http://www.gnpplus.net/content/view/1511/1/


9. Ibid. p.38.
It is now generally understood that HIV is acquired more easily in the presence of untreated STIs, so effective diagnosis and treatment of STIs, along with the use of condoms, can reduce the risk of HIV infection. It is also a vital part of positive prevention that STIs are effectively diagnosed and treated in people living with HIV. Ulcerative and inflammatory STIs can increase HIV shedding and infectiousness, while treatment of STIs can lead to decreased shedding\(^\text{10}\). Some STIs can also be more severe and cause health complications for people living with HIV, particularly those with low CD4 counts\(^\text{11}\). The recent Swiss Guidelines\(^\text{12}\) state that HIV-positive people on ART and with a suppressed viral load for at least six months have little chances to sexually transmit HIV. However, in the presence of an untreated STIs the effectiveness of ART as a HIV transmission prevention method is reduced. All people living with HIV need regular sexual health checks when initially diagnosed with HIV and followed at regular subsequent intervals, particularly if they have multiple sexual partners.

Family planning is important for people living with HIV and contributes substantially to the prevention of mother-to-child transmission of HIV. Too often, however, reproductive health services sensitive to the needs of people with HIV are not available\(^\text{13}\). While positive people may have similar family planning needs to the general population, including avoiding unintended pregnancy, accessing contraception methods and safe abortions when required, they also have some unique needs such as preventing HIV transmission to their child. Women living with HIV continue to face stigma and discrimination in many parts of the world, including coercion into sterilisation and termination. Men living with HIV are often not involved or consulted on their reproductive intentions. Women and men living with HIV can and do have healthy families and it is vital that service providers recognise this and work collaboratively with them to safeguard their rights.

People living with HIV need to receive information about their sexual and reproductive health rights, and be empowered to make informed choices that will improve their health and well-being. Women living with HIV are particularly vulnerable to the increased risk of cervical cancer, and abnormal cervical cytology (abnormal cells of the cervix)\(^\text{14}\). The presence of the human papilloma virus (HPV) is more frequent among women living with HIV but it also affects men living with HIV. There is higher prevalence of anal HPV among men who have sex with men who are living with HIV which increases the risk of anal cancer.

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**The Swiss Guidelines**

In February 2008 the Swiss Federal Commission on HIV/AIDS issued guidelines based on two studies and extensive research of available literature. The Guidelines stated that:

An HIV-infected person on antiretroviral therapy with completely suppressed viraemia (“effective ART”) is not sexually infectious, i.e. cannot transmit HIV through sexual contact. This statement is valid as long as:

- the person adheres to antiretroviral therapy, the effects of which must be evaluated regularly by the treating physician, and
- the viral load has been suppressed (<40 copies/ml) for at least six months, and
- there are no other sexually transmitted infections.

While more research needs to be conducted, it is generally accepted that effective medication and good viral control is extremely effective in lowering the likelihood of HIV transmission. In most countries the recommendation remains to use condoms and a water based lubricant during vaginal and anal penetrative sex. Furthermore there may be reasons other than reducing the risk of HIV transmission for using condoms. One of them is that the presence of STIs increases the risk of transmission and can adversely affect the health of people living with HIV.

10. Ibid. p.23.
11. CD4 cells are specialized white blood cells that play an important role in the body's immune system.
12. HIV-positive individuals without additional sexually transmitted diseases (STD) and on effective anti-retroviral therapy are sexually non-infectious. 2008. ‘Swiss Guidelines’, www.aids.ch/efragen/pdf/swissguidelinesART.pdf
What can you do?

People living with HIV

1. **Avoid contracting STIs**: Practice safer sex to protect yourself and your partner by always using male or female condoms, water base lubricant when having penetrative sex or practice non-penetrative sex. Be aware of how HIV and STIs are transmitted as this will help understanding risks and will place you in a better position to protect yourself and your sexual partner.

2. **Have regular sexual health check-ups**: Ensure you have regular sexual health check-ups, especially if you have more than one sexual partner; your sexual partner has other sexual contacts; or if you or your sexual partner(s) have any signs or symptoms of an STI. Signs and symptoms of an STI can include a rash, ulcers, lumps, discharge or pain in the ano-genital region. However, many STIs do not cause any noticeable signs or symptoms so a regular sexual health check-up is best, along with practising safe sex.

3. **Find a knowledgeable health provider**: Find a health care provider who has up-to-date knowledge of sexual and reproductive health. Ideally this person should also have good knowledge of HIV or is at least willing to communicate with your regular HIV health care provider if required. Some people find discussing sexual and reproductive health embarrassing so it is important to find a health care provider who you can trust and who understands your particular needs and lifestyle. You need to be honest with your doctor about your actual sexual practices, which may include activities such as anal sex, sex with multiple partners or sex between you and people of the same gender (i.e. men with men or women with women). If you do not feel you can be honest with your present health care provider, consider finding another one.

4. **Understand your medications**: Make sure you understand what any medications you have been prescribed are for, how long you should take them for, how you should take them (e.g. with or without food) and any potential side-effects to watch out for. Take your medications as ordered and finish the entire course of tablets even if the signs and symptoms of your STI appear to have gone. Please check if your sexual partner will also need to undergo treatment – if your partner does not take treatment at the same time as you, then there is high risk of re-infection.

5. **Seek advice on family planning methods**: Seek out the latest information on contraception and find family planning method/s that are most suitable for you. Discuss and check this information and your choices with people you trust, including your health care provider and if possible other positive people.

6. **Consider dual protection**: Consider using dual protection (i.e. using condoms combined with other contraceptives such as hormonal contraceptives, IUD or the pill) if you want to avoid becoming pregnant at the present time.
7. **Seek advice on safe pregnancy:** If you desire to become pregnant, seek advice on getting pregnant safely. This is especially important if you are in a sero-discordant relationship (i.e. you and your partner are of different HIV status, one positive and the other negative) or you have other health issues. If you are a woman living with HIV there is now much less risk of you passing on HIV to your newborn child if you follow appropriate precautions, including taking a course of specially prescribed ART for you and your baby and using safe delivery methods. You will also need to look into safe infant feeding options and choose one that is appropriate to your personal circumstances. Talk to your doctor, health provider or midwife, and seek out more information from your local HIV positive group.

8. **Access safe abortion services:** If you decide to terminate your pregnancy, discuss it with a service provider and obtain more information and guidance on available options for accessing safe abortion services. Seek services offered in a safe environment under the supervision of a health care provider. Avoid using unsafe methods such as ingesting herbs or other poisonous substances or inserting sharp objects into your vagina – as they can cause infections and seriously damage your health.

9. **Be aware of the risks:** If you are a man who is having sex with other men and who sometimes decides to practice unsafe sex with HIV-positive men (sero-sorting) be aware of the risk of contracting other STIs, particularly hepatitis B and C. Try to always use condoms with your casual partners, even if he is also HIV-positive and undergo regular sexual health checkups.

10. **Ask for cervical screening:** If you are a woman living with HIV, ensure your health care provider offers you cervical screening (also known as smear test) when you are first diagnosed with HIV and then at regular (e.g. annual) intervals depending on the results of the first test. Talk to your doctor about your cervical screening and ask questions to understand what tests are for and make sure you receive the results.

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### Service providers

1. **Stay informed:** Keep up-to-date with the latest information about HIV and related illnesses and their connections with sexual and reproductive health issues. This is especially important for people living with HIV with regards to STI treatment, safe pregnancy and PMTCT.

2. **Offer regular sexual health check-ups to your clients:** Ensure that any clients living with HIV receive a full sexual health check-up on initial HIV diagnosis and at regular intervals, especially if they have multiple sexual partners. The check-up should include assessing their history of past STIs, current symptoms and recent risk behaviours. A full physical examination, including of the ano-genital region, should be conducted, especially at initial HIV diagnosis, along with a full STI laboratory testing if available.
3. **Diagnose and treat STIs effectively:** Make sure you effectively diagnose and treat STIs in all people living with HIV. Some STIs, such as herpes simplex virus (HSV), can be severe and cause increased health complications for people living with HIV, particularly those with low CD4 counts.

4. **Prevent re-infection:** Treat any sexual partners of people with a diagnosed STI to prevent re-infection. Creative ways to do this could include providing additional courses of treatment to your client for their sexual partners which they can take away.

5. **Respect your client’s rights:** Establish good relations with your positive clients and respect their decisions. Every person, including a person living with HIV, has the right to have children. If managed correctly, positive women becoming pregnant and having healthy children should incur minimal risk to their partner, themselves or their newborn child. Women also have the right not to have children. You should provide positive women and their partners’ (regardless of marital status) access to the full-range of contraception options, including the male and female condom, to avoid unintended pregnancies. It may be appropriate for positive women to use dual protection (i.e. condoms and contraceptives) to decrease the risk of an unintended pregnancy.

6. **Facilitate access to abortion services:** Ensure access to safe and non-coercive abortion services to HIV positive women who do not want to continue their pregnancies – following existing national laws and protocols. Facilitate referrals to safe providers if the services are not available in the health facility where you work and follow up with the referral centre and/or the client to ensure her well-being.

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### What can you do?

#### Policy makers/Advocates

1. **Protect the rights of people living with HIV:** Advocate for the protection of the rights of people living with HIV, specifically the right to self determination. Many people living with HIV have experienced, and continue to experience incidences of forced testing, pregnancy terminations, sterilisations and STI screenings, as well as denial of access to essential health services.

2. **Challenge stigmatizing community attitudes:** Challenge community beliefs and attitudes that reinforce stigma and discrimination against people living with HIV, particularly negative perceptions that deny the right of people living with HIV to have children or relationships.

3. **Advocate for the removal of restrictive laws:** Repeal any laws and policies that hinder people accessing SRH services, including those that restrict young people from accessing SRH services without parental permission; abortion laws and sodomy laws that condemn same sex relationships.
How do we know this works?

In Madurai District, India, the Family Planning Association of India (FPA India) has introduced a combination of strategies to promote positive prevention among people living with HIV. These strategies combine:

- **Individual health promotion:** Health care providers and people living with HIV were trained as peer educators to provide information to people living with HIV on prevention and treatment of STIs and opportunistic infections, positive living, nutrition, hygiene, treatment literacy and adherence;

- **Provision of services:** Services including family planning, STI diagnosis and treatment, antenatal and postnatal care, and referrals for treatment and care are offered by FPA India at the community care centre in Madurai and through a mobile unit in the rural areas;

- **Community mobilization:** Community rallies and meetings and dissemination of information through radio spots have helped to address HIV related stigma and discrimination at household, community and institutional level, and raise awareness of the needs and rights of people living with HIV.

FPA India has found that this holistic approach has been instrumental in improving the well-being of people living with HIV and facilitating access to a wider range of services. Community mobilization led by people living with HIV has helped create awareness of the sexual and reproductive health and prevention needs of people living with HIV, while mobile clinics and outreach workers ensured that people living with HIV had easy access to information and services. Outreach workers also refer people to the community care centre for ART, CD4 cell count, and management of side effects and opportunistic infections.

One of the highlights was the provision of appropriate sexual and reproductive health information to people living with HIV. Service providers were trained in safe conception; pregnancy and delivery which made them feel more confident about counselling HIV-positive people about their reproductive options. As a result, people are receiving information about the different methods available for planning a safe pregnancy and choosing a family planning method, depending on their individual circumstances.

Things to consider:

- Knowledge about the risk of HIV transmission for sero-discordant couples when trying to become pregnant is advancing all the time. This includes the findings that when a person living with HIV is on effective ART the risk of transmitting HIV is low. Unprotected sexual intercourse when these conditions are met therefore carries little risk of HIV transmission but should be promoted only on those days when the chances of conception are maximised. There is also ongoing research into the use of pre-exposure prophylaxis with ART which can be taken by the HIV negative partner before practising unprotected sex.

- Using ART for the prevention of mother-to-child transmission (PMTCT) of HIV has been proven to be highly effective and achievable even in resource poor settings. A four prong approach to PMTCT should be promoted, including the provision of family planning for HIV-positive mothers who want to avoid getting pregnant or space their next pregnancy and ongoing treatment after delivery for the mother, the baby and other family members. Your national PMTCT guidelines should correspond to the latest World Health Organization PMTCT guidelines¹⁵.

- There continues to be many documented situations of discrimination in the delivery of sexual and reproductive health services that violate the human rights of people living with HIV. Many of these situations appear to be linked to decisions made by individual service providers based on their personal, moral and/or religious beliefs, particularly in relation to marginalised populations such as single and young women, sex workers, transgendered people, men who have sex with men and people who use drugs. Individual service providers who are unable or unwilling to provide non-discriminatory sexual and reproductive health services must ensure their clients are referred to accessible services that will.

2. Delaying HIV disease progression

What does it mean for people living with HIV?

Positive people want and deserve the right to live long and healthy lives. With the recent increase in the range, effectiveness and access to ART and opportunistic infection (OI) treatment, HIV can, in many cases, be viewed as a manageable chronic illness. Delaying HIV disease progression is only one component of living a long life, positive people also want to improve their health and well-being and need support to explore issues such as healthy eating, adequate exercise, avoiding other illnesses, reducing harmful behaviours, getting emotional support and building self-esteem. People living with HIV do not just want to be seen as someone with a viral disease that needs to be medically treated. They also want to be seen as a whole person who is empowered and supported to delay HIV disease progression and improve their overall health and well-being.

Why is it important?

Over a quarter of a century of experience with HIV has taught us much about this infection. In most cases, without effective ART and OI treatment when needed, the natural disease progression of HIV is to lead to AIDS and eventually death. The average time for this progression of untreated HIV to AIDS is about ten years but this can vary widely depending on many factors such as age, virological factors and health status. In order to prevent HIV disease progression it is vital that OIs are prevented and/or diagnosed and treated promptly as they emerge, ART is commenced when needed, adherence to the ART regime is maintained and overall health is regularly monitored. Many people living with HIV are also co-infected with other infections including hepatitis B or C, malaria and tuberculosis (TB). It is also vital that these infections are managed effectively, along with their HIV infection. These interventions must be carried out through a partnership between the person living with HIV and their health providers, and treatments must match the needs of the positive person. See box 2 for a list of key interventions.

Box 2

Key interventions for adult and adolescents living with HIV

WHO has published a set of guidelines including thirteen effective, evidence-based interventions for people living with HIV in resource-limited settings that are “simple, relatively inexpensive, can improve the quality of life, prevent further transmission of HIV, and for some interventions, delay progression of HIV disease and prevent mortality.”

- Psychosocial counselling and support;
- Disclosure, partner notification and testing and counselling;
- Co-trimoxazole prophylaxis;
- Tuberculosis counselling, screening and prevention;
- Preventing fungal infections;
- Sexually transmitted and other reproductive tract infections;
- Preventing malaria;
- Selected vaccine preventable diseases (hepatitis B, pneumococcal, influenza and yellow fever);
- Nutrition;
- Family planning;
- Preventing mother-to-child transmission of HIV;
- Needle-syringe programmes and opioid substitution therapy; and
- Water, sanitation and hygiene.


To enable people living with HIV to delay HIV disease progression and improve their health and well-being there is a need to strengthen community actions in identifying priorities, making decisions, and planning and implementing strategies. Empowering individuals and communities of people living with HIV requires equitable access to information, education and life skills through a real investment of effort, time and resources. Positive people need skills and knowledge development in areas such as basic HIV and related diseases, treatments, normal body functions, nutrition, exercise, mental health and safe behaviours. We need to recognise that HIV-positive people are the ‘living experts’ in terms of living and thriving with HIV and will be the ones who can develop and drive innovative, effective interventions such as peer support programs. Positive people are part of the solution, not the problem!

Positive prevention is essentially for people who have been diagnosed with HIV but the majority of HIV-positive people remain undiagnosed, and so are not receiving basic HIV treatment and care services. For positive prevention to work effectively, it is vital that greater efforts are put into reducing HIV related stigma and discrimination. Health services, with the support of people living with HIV, can do more to increase efforts for early diagnosis through voluntary counselling and HIV testing (VCT). This could include employing positive people in clinics as peer support workers for people newly diagnosed with HIV as well as expanding psycho-social support for people living with HIV.

People living with HIV

1. **Stay up to date:** Seek out the latest information on HIV and related illnesses, including progression and treatment. Also look for information on how to improve your health and well-being as a positive person. This information can come from a variety of sources, including health workers, books, magazines, radio, television and the internet, but make sure you double-check the reliability of this information before making any decisions that may affect your health.

2. **Find a holistic health care provider:** Find a health care provider who has up-to-date knowledge of HIV, who you trust and who you feel you can communicate well with. Your health care provider should also take an interest in you as a ‘whole person’, not just your virus. Prepare questions before your appointment and make sure all are answered to your satisfaction. If necessary ask your health care provider for clarification about any issues and ensure you are happy with any decisions made about your health.

3. **Look out for health problems:** Look out for any health problems that arise between your regular visits to your health care provider and make sure you follow-up these issues as soon as possible, either with your health care provider or other health care workers. Ask questions when your health care provider orders regular monitoring tests (e.g. blood tests) so you understand what these tests are for and find out the results.
4. **Understand your medications:** Make sure you understand what any (prescribed) medications are for, how long you should take them for, how you should take them (e.g. with or without food) and any potential side-effects to watch out for. Take your medications on time!

5. **Adhere to your ART:** Adhering to your medication (taking the correct dose of your medications on time) is vital, and especially so for ART. Assistance devices such as pill boxes/trays and alarm watches may help you to adhere to your treatment schedule. Some places have strategies such as ‘peer support’ or ‘buddies’, where other HIV-positive people provide support for your treatment adherence. Get support from family and friends, and tell your health care provider as soon as possible if you are having any trouble with taking your medications.

6. **Discuss the use of complementary medicines:** Discuss with your health care provider the use of complementary (sometimes called ‘alternative’ or ‘traditional’) medicines and therapies such as vitamin supplements, acupuncture and herbal medicines to make sure they do not have any negative impact upon your HIV care. Many people living with HIV use these complementary medicines to make them feel healthier and to help with the side-effects of their medications. Remember there is overwhelming scientific evidence showing that ART is the only treatment that will effectively suppress HIV and there is currently no scientifically proven cure for HIV.

7. **Look after your physical health:** Make a long-term plan on ways to reduce any of your current behaviours that may harm your health, such as the use of alcohol and other drugs, and smoking. Talk to your doctor about any available methods to help you reduce these behaviours.

8. **Eat well and exercise:** Eat a variety of fresh foods and try to have regular healthy meals. Find out your ideal body weight and try to maintain it. Dietary changes can also help with the management of symptoms such as diarrhoea and nausea, so consult your health care provider for advice if needed. Also get regular exercise, even going for a walk with a friend, doing some stretches, or working in the garden for just 30 minutes each day will benefit your health.

9. **Look after your emotional health:** Take care of your emotional health. Counselling can help you learn some new skills to cope with living with HIV. Consider joining a HIV-positive peer support group as sharing your experiences of living with HIV, good and bad, with other people living with HIV can also help you feel better.

10. **Get involved:** Consider becoming involved in your local support group, volunteer for an organization or get involved in peer education activities to meet other positive people, learn new skills and help to make life better for all positive people in your community.
Section 2

What can you do?

1. **Stay up to date**: Keep up to date with the latest information on HIV and related illnesses. Knowledge is rapidly changing and new treatments and monitoring methods are continuing to be developed.

2. **Support your clients**: Establish a good relationship with your HIV-positive clients and support your client’s decisions. Better health outcomes will be achieved when clients understand and agree with any interventions you are recommending.

3. **Take a holistic view**: Remember to view people living with HIV as a whole person, not just a virus to be controlled. As well as HIV, they may have other health issues that need attention, plus you are aiming to improve their health and well-being, so psychosocial issues are just as important as medical issues.

4. **Treat clients as individuals**: Treat your clients as individuals and respect their differences in terms of gender, age, sexual orientation and lifestyle choices. Offer high quality services and respect client’s decisions and choices regarding their health and well-being.

5. **Ensure appropriate follow up care**: Promote attendance to routine medical health examinations to monitor the CD4 cell count, the timely diagnosis and treatment of OI and timely access to ART. Particular considerations should be taken to ensure every person living with HIV receives the highest standard of medical care available.

6. **Establish a strong referral system**: Establish a strong referral system to services that cannot be provided in the health facility where you work, for example for the diagnosis and treatment of TB, hepatitis, cancers and any other illness. A strong system should include the use of referral forms, development of agreements with other health facilities or facilitate the process by accompanying clients to the referred services when it is located in the same health facility.

7. **Promote treatment adherence**: Build a close relationship with each client and have open communication to better understand your client’s everyday commitments, lifestyle and any changes in their lives that may affect their treatment adherence. For example having a new job with different work hours making eating regular meals with medication difficult; increased family responsibilities resulting in greater financial burden; change in relationship status becoming single or entering into a new relationship. Develop individual treatment adherence plans so your client is able to manage her/his treatment effectively.

8. **Look after the health of HIV-positive clients who are using drugs**: If your client is using drugs and want to access treatment for her/his addiction, ensure HIV care is linked to effective and evidence-based drug treatment programmes, including opioid substitution therapy (OST) for people using opioid-based drugs and other type
of treatment programmes for people using amphetamine-type stimulants (ATS). There is strong evidence showing the positive health effects of these programmes in maintaining good health and ensuring adherence to HIV treatment regimens.

9. **Keep informed of the latest guidelines and protocols:** Guidelines and protocols for the provision of treatment, care and support are regularly reviewed. Ensure you use the latest guidelines and protocol to inform your practice.

10. **Involve people living with HIV:** The experience and expertise of people living with HIV is essential for informing the development of services that address their specific needs. They can also act as expert clients, peer educators and peer community health workers to provide psychosocial support to other people living with HIV. Create opportunities to involve people living with HIV in your health care facility and promote training and other strategies to develop their skills.

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**Policy makers/Advocates**

1. **Advocate for sustainable funding:** Advocate for ensuring sustainable funding and resource allocation for quality HIV care, treatment and support services to ensure HIV-positive people remain healthy and on treatment. HIV is now becoming a chronic manageable illness and it is vital to ensure the long term sustainability of HIV treatment, including ancillary services such as counselling and psychosocial support.

2. **Promote the involvement of people living with HIV in treatment and care services:** People living with HIV can offer their skills and experience to lessen the burden on health services to cope with an expanding demand for HIV care. Improving positive people’s health and longevity will have long-term economic benefits for the person, their family, their community and, on a larger scale, the national economy.

3. **Promote quality of services:** Ensure that all people living with HIV are able to access treatment, care and support services from well trained staff from either government or non-governmental health care services, including mobile clinics and community health workers. While availability of drugs may be adequate, the human capacity and accessibility of high quality comprehensive services may not always be available, especially in rural areas.
How do we know this works?

In 2005, Family Health Options Kenya (FHOK) started to implement a project to integrate HIV treatment and care into existing sexual and reproductive health services. The Models of Care project was introduced in six clinical sites. The key objectives of the project were to:

- Increase access to comprehensive HIV care including ART for HIV-positive people at clinic and community sites.
- Strengthen capacity of FHOK to integrate HIV within existing sexual and reproductive health services.

A key feature of the project was the recruitment of people living with HIV as community health workers (CHW) to deliver services in the community. Two CHWs were recruited (one of whom is living with HIV) to visit project sites two or three times each week. They contact households or individuals in need of clinical services and provide food supplements, everyday items such as clothes, counselling, free medication and education on basic hygiene, HIV and AIDS, family planning and other sexual and reproductive health information. CHWs pay house-calls to two to four clients on each community visit; give community ‘healthy talks’; work with youth groups on community mobilization; and support clinic staff in their monthly community outreach visits where they provide on-site clinical services – including VCT, family planning and other key services. The CHWs also organise psychosocial support group meetings and provide treatment adherence counselling to people on ART.

The greatest impact of the project was the support people living with HIV received in obtaining ART. FHOK is an approved provider of antiretroviral (ARV) drugs as part of the national roll-out, and as a result is able to provide ART to project beneficiaries. The project also contributed to changing peoples’ attitudes towards people living with HIV with a resulting decrease in stigma and more people living with HIV accessing services – especially women who are now using family planning and PMTCT services.

Source: Models of Care Project, Review of Vulnerable Group Programmes, IPPF, June 2009.

Things to consider:

- Continuing advances in new ART regimens and knowledge about HIV means that it is vital to keep up-to-date with the latest information and share this knowledge with colleagues and positive people.
- HIV health care is a relatively new field so it is very important that services and products are continually monitored for their quality and effectiveness. An example of this is concern recently expressed about the quality of some ‘generic’ antiretroviral drugs.
3. Promoting shared responsibility to protect your sexual health and reduce the risk of HIV transmission

What does it mean for people living with HIV?

Everyone shares the same responsibility to protect themselves and others from HIV. Taking responsibility and making informed decisions about one’s own sexual behaviour can be in itself very empowering. The responsibility for HIV prevention is a shared one and should be not solely placed among people who know their HIV status. This is especially important given that the majority of people living with HIV are not aware of their status. While there is a clear benefit in talking openly about HIV, many HIV-positive people find it difficult to do so because of unequal gender relationships, fear of being discriminated against or previous negative experiences. The decision to disclose an HIV positive status should be voluntary and it is the choice of the person living with HIV to decide when and to whom to disclose. They should not feel pressured to disclose their status by their partners, the law, medical professionals or peers. Most people living with HIV do take positive actions to protect their sexual health and their partner’s.

Why is it important?

Human rights principles underpin the concept of shared responsibility - principles that equally protect and promote the human rights of everyone regardless of HIV status. Addressing the prevention needs of people living with HIV depends on promoting an environment in which their rights are respected. This includes the right to the highest attainable level of health\(^\text{17}\) - including physical, mental, and social well-being as well as sexual and reproductive rights\(^\text{18}\), the right to life, and the right to privacy, which includes the rights to non-discrimination, confidentiality and informed consent (refer to box 3: Sexual rights: an IPPF declaration).

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**Sexual rights: an IPPF declaration (2008)**

Sexual rights are human rights related to sexuality, and they underpin the approach and the contents of this publication. Sexual rights are constituted by a set of entitlements related to sexuality that emanate from the rights to freedom, equality, privacy, autonomy, integrity and dignity of all people.

The ten sexual rights are:

1. Right to equality, equal protection of the law and freedom from all forms of discrimination based on sex, sexuality or gender.
2. The right to participation for all persons, regardless of sex, sexuality or gender.
3. The rights to life, liberty and security of the person and bodily integrity.
4. Right to privacy.
5. Right to personal autonomy and recognition before the law.
6. Right to freedom of thought, opinion and expression; right to association.
7. Right to health and the benefits of scientific progress.
8. Right to education and information.
9. Right to choose whether or not to marry and to found and plan a family, and to decide whether or not, how and when, to have children.
10. Right to accountability and redress.

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\(^{17}\) The right to the highest attainable standard of health as a ‘state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,’ and as ‘one of the fundamental rights of every human being, without distinction of race, religion, political belief, economic or social condition,’ was recognised in 1946 with the adoption of the Constitution of the World Health Organization (WHO), World Health Organization (WHO) (1948). Constitution of the World Health Organization. New York: UN.

A new trend has started to emerge in many countries, where laws have been introduced to criminalize HIV transmission and exposure to HIV infection. In these countries failure to declare an HIV positive status to a sexual partner can lead to a fine or imprisonment – even in situations where the couple have practised safer sex. Laws criminalizing the transmission/exposure of HIV must be strongly opposed because:

- The criminal law is in fact a blunt instrument for ‘controlling’ the intimate behaviours through which HIV can be transmitted;
- It is a fundamental breach of human rights to generate legislation that can only ever apply to a specific group of people (in this case people living with HIV);
- The application of law can do more harm than good and undermine prevention efforts by re-enforcing instead of transforming the social inequalities that determine health, human dignity, equality and freedom;
- Stigma and discrimination can have a negative influence on the ability of people to access the information, services and support they may need to deal with their HIV status. Stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexual orientation, behaviour and race. The decision to disclose or not to disclose HIV status can be influenced by previous experiences of stigma and discrimination which hinders access to vital services, including prevention, treatment and care. The fear of rejection, blame or violence is often there when decisions around disclosure are made. There are many instances where people living with HIV choose not to access certain services or believe their choices are limited due to their status. A person who is newly diagnosed may feel compelled to disclose their status to another party, not realising that they have the right to their own privacy.

Sexual health is the responsibility of both partners.
What can you do?

People living with HIV

1. **Be responsible:** Take responsibility to protect yourself and your sexual partner and encourage your partner to do the same.

2. **Be familiar with the law:** Get information and be aware about any laws in your local jurisdiction which criminalize specific behaviours – for example illicit drug consumption, sex work, sodomy laws or HIV transmission. Knowing the law can help people when rights may have been violated. Getting information from peers or outreach services could help you understand the legal context and to protect your rights.

3. **Know your rights:** You need to be aware of your rights as a person living with HIV. This includes the right to health, dignity, freedom of expression and movement, and the rights to privacy, confidentiality and informed consent.

4. **Assess when to disclose your HIV status:** Think about your current situation and assess the obstacles you might face regarding disclosure. It is important that you consider all aspects of disclosing your status, including the benefits and potential drawbacks and be prepared to deal with the reactions – both positive and negative.

5. **Understand the risk of HIV transmission:** Ensure you have up-to-date and full information on what constitutes risk of transmission. This includes knowing the relative risks of various sexual activities (oral sex, masturbation, kissing, penetrative vaginal and anal sex, rimming etc.) and the implications they may have for HIV transmission.

6. **Seek psychosocial support services:** Find a counselling service or support group with which you feel comfortable, if you need it. Such services can provide extra support to that provided by your health care provider, family or friends. Services from professional counsellors may be available in your community from whom you can seek advice and support. Your health care provider or a local HIV organization should be able to recommend appropriate places where you can go.

7. **Identify legal services:** Seek out information and collect contact details of organizations and networks that can offer legal information and services where you can request information or support, in case you need it.

8. **Promote the concept of shared responsibility:** The responsibility for HIV prevention cannot rely solely on people who know their HIV status. Use opportunities that may arise to share this concept with your partners, friends and colleagues.

9. **Advocate against laws that criminalize HIV transmission/exposure:** Work with other people living with HIV to advocate against laws that specifically criminalize the transmission or exposure of HIV. Advocate for the revision of laws that criminalize certain behaviour such as the sodomy law which can have a negative impact upon HIV prevention.

10. **Understand human rights:** Advocate for the inclusion of legal literacy components in positive prevention programmes to build capacity of people living with HIV to understand human rights, the law and its implications for HIV prevention.
Positive Prevention

Section 2

What can you do?

Service providers

1. **Know the rights of people living with HIV**: Be knowledgeable about the rights of people living with HIV and seek to develop your own capacity in this area which will support your work in promoting positive prevention.

2. **Respect the rights of people living with HIV**: Respect the rights of people living with HIV to have a full and satisfying sex life; work with both people living with HIV and their partners to achieve this.

3. **Keep up to date with new developments**: Ensure you have accurate and up-to-date knowledge on the risk factors for HIV transmission and the potential benefits of treatment as prevention. Ensure you discuss this information with your HIV-positive clients and provide support to assess their risks.

4. **Seek consent for the services offered**: Ensure the rights of clients are respected at all times in the health facility and during consultations. All services should be provided with the full consent of the client and should not be selective based on status, sexual orientation or lifestyle choices.

5. **Be aware of legislative requirements**: Support people living with HIV with advice on relevant laws and rights issues and refer them to appropriate organizations when needed. These could also have an impact on your work.

6. **Promote a stigma free environment**: Promote a stigma free working environment in the health facility, putting into practice the principles of a workplace policy. This should also support HIV-positive health care workers who may be afraid of disclosing their status for fear of losing their job or being discriminated against.

7. **Provide support for disclosing HIV status**: Provide support and counselling on issues around disclosure of HIV status; be sensitive with the process and the advice you provide. The client has the right to make final decisions regarding disclosure and you cannot disclose their status with their sexual partners without their informed consent – even in situations where their sexual partner(s) may be at risk.

8. **Maintain confidentiality**: Remember your responsibility as a health provider not to pass on confidential information without the consent of your client. The only exception is an official legal investigation but you should seek advice on the balance between confidentiality and provision of information for the investigation.

9. **Build partnerships**: Establish strong referral systems and partnerships with legal support agencies and human rights lawyers.

10. **Disseminate accurate information regarding HIV transmission**: In healthcare facilities, make available information and materials that articulate the legal situation regarding HIV transmission and the rights of people living with HIV.
1. **Promote a rights-based approach**: Promote the adoption of a legal and policy framework to support the rights of all people to have a full and enjoyable sex life and create a supportive environment for positive prevention programmes.

2. **Repeal punitive laws against people living with HIV**: Work specifically to repeal laws that criminalize HIV positive people, for example laws that criminalize HIV transmission, restrict freedom of movement or the right to work.

3. **Address gender-based violence**: Advocate for strong support systems for women affected by gender-based violence and support the introduction of gender transformative programming in all strategies.

### How do we know this works?

In 2009, the Association Rwandaise pour le Bien-Etre Familial (ARBEF) in collaboration with other civil society organizations and the Rwandan national network of people living with HIV, embarked upon an advocacy initiative which focussed on amending a draft Bill on Reproductive Health that was being passed by Senate.

The Bill, while it was considered to be generally well intentioned, was found to be too narrow in its definition of reproductive health and was not in line with universally adopted human rights principles. There were a number of specific concerns, most notably the references made to mandatory HIV testing and certain issues relating to people living with HIV. The Bill included an article forcing all married couples to undertake an HIV test and disclose their HIV status to their spouse. This contradicts key human rights principles on privacy and autonomy and undermines efforts to promote shared responsibility. Legally requiring all HIV-positive people to disclose their HIV status regardless of whether or not there is a supportive environment and safe opportunity to do so increases HIV-related stigma and reduces incentives to discover one’s HIV status.

A national meeting was organised by ARBEF and other civil society activists to debate the controversial contents of the Bill. This intervention from civil society, in particular the articulation of alternative language to strengthen the Bill, has seen it return to the lower chamber of Parliament for review. The role of civil society in this intervention has been crucial in reviewing the Bill, promoting human rights principles, and potentially blocking discriminatory legislation that would have infringed the human rights of people living with HIV.
Things to consider:

- Human rights abuses need to be recorded and documented so as to inform advocacy efforts.
- National criminal laws change regularly. It is essential, therefore, that organizations stay abreast of these changes and provide this information to people living with HIV.
- Arguments against the criminalization of HIV transmission or exposure must be based on strong scientific evidence about transmission risk, and solid evidence on the negative impacts of such laws on HIV prevention and HIV-related stigma.
- It is clear that effective treatment reduces infectiousness and so transmission risk. More research is required in this area, and the results integrated into health policy and legal frameworks.
- Most new infections occur in cases where the HIV-positive partner does not know his or her status. Efforts must be made to encourage voluntary HIV testing of those vulnerable to HIV or those who know they might have been at risk of exposure.
Section 3

In this section

- At a glance: Key strategies to promote positive prevention
Section 3

At a glance: Key strategies to promote positive prevention

This section outlines a number of strategies that should be considered when scaling up or strengthening positive prevention programmes. The first overarching strategy outlines the activities all positive prevention programmes should include. Then, recognising that people living with HIV are not a homogenous group but have very differing needs, specific interventions are highlighted for different populations. These include: men and boys, men who have sex with men, people who use drugs and their sexual partners, sex workers, transgendered people, women and girls and young people. The interventions have been categorised according to the three pillars outlined in Section 2: Protecting their sexual and reproductive health; Delaying disease progression and Promoting shared responsibility. This list is not exhaustive but simply shows the range of options available to all those involved in securing the right to health for people living with HIV. The three pillars sit on a continuum of positive prevention and cannot be considered in isolation so certain activities appear across more than one of the action areas.

<table>
<thead>
<tr>
<th>OVERARCHING STRATEGY</th>
<th>Protect their sexual and reproductive health</th>
<th>Delay disease progression</th>
<th>Promote shared responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure provision of quality, non-judgemental sexual and reproductive health information and services through drop in centres, static and/or mobile clinics that are accessible, acceptable and affordable.</td>
<td>Ensure all people living with HIV receive the highest possible quality of healthcare services without discrimination, respecting their rights to confidentiality, privacy and informed consent.</td>
<td>Inform people living with HIV of their rights to privacy, confidentiality and informed consent.</td>
<td></td>
</tr>
<tr>
<td>Ensure interventions are delivered within a framework of sexual health, which includes discussions of relationships, self-esteem, body image, sexual behaviours and practices, sexual satisfaction and pleasure, sexual functioning and dysfunction, stigma, discrimination, and alcohol and drug use.</td>
<td>Encourage people living with HIV to attend routine medical health check-ups to monitor their CD4 cell counts, for timely diagnosis and treatment of OI and to facilitate access to ART when needed.</td>
<td>Promote changes in policies and laws that criminalize HIV transmission.</td>
<td></td>
</tr>
<tr>
<td>Ensure appropriate access to quality male and female condoms and water-based lubricants and promote social condom marketing.</td>
<td>Establish a referral system to non-health related services such as legal and social support.</td>
<td>Promote strategies to address HIV related stigma and discrimination and assist the establishment of support groups and other strategies that build trust and solidarity among people living with HIV.</td>
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<tr>
<td></td>
<td>Promote treatment adherence through peer education, support groups, buddy systems and other community-based strategies.</td>
<td>Promote social and personal development that can contribute to increased life skills of people living with HIV and raise awareness on how to take control over decisions affecting their lives.</td>
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</tbody>
</table>
## OVERARCHING STRATEGY (cont.)

<table>
<thead>
<tr>
<th>Protect their sexual and reproductive health</th>
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<tbody>
<tr>
<td>Promote consistent and correct condom use with regular and casual sexual partners; discuss safe sex strategies and the importance of using a dual protection method – combining condoms with another contraceptive to prevent against STIs and unwanted pregnancies.</td>
<td>Ensure access to TB diagnosis and treatment programmes.</td>
<td>Promote strategies that link health interventions with micro-credit and skills development strategies to promote economic empowerment and build social capital.</td>
</tr>
<tr>
<td>Promote routine screening, diagnosis and treatment for STIs.</td>
<td>Ensure that clinical guidelines and service delivery manuals are sensitive to the specific health needs of all clients, and health care providers are properly trained to address these needs.</td>
<td>Support people to make decisions regarding disclosure based on the right to choose if and when to disclose their HIV status.</td>
</tr>
<tr>
<td>Facilitate access to family planning services, emergency contraceptives and abortion services when needed.</td>
<td>Provide diagnostic testing for viral hepatitis and vaccination for hepatitis A and B. Ensure timely access to treatment for hepatitis B and C, when clinically indicated.</td>
<td>Liaise with the police force and other gatekeepers to ensure key populations are not prosecuted or criminalized. In the event of the incarceration of people living with HIV, promote ongoing provision of essential health services in prisons, particularly for people on ART and opioid substitution therapy (OST) programmes.</td>
</tr>
<tr>
<td>Provide counselling services and psychosocial support to deal with issues such as disclosure of HIV status, sexual health, sexuality, relationships, addressing gender-based violence, risk reduction and substance use.</td>
<td>Ensure access to care for victims of violence, and referral to violence prevention programmes.</td>
<td>Involve people living with HIV in the design, implementation and evaluation of positive prevention programmes, the provision of services, and in decision and policy making.</td>
</tr>
<tr>
<td>Create safe spaces, such as drop-in centres, where groups of people living with HIV can meet, access services, and receive food, clothes and shelter.</td>
<td>Provide information on nutrition and diet and encourage regular exercise.</td>
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</tbody>
</table>
## MEN AND BOYS

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>- Provide counselling and psychosocial support to men and boys living with HIV to deal with issues such as disclosure of HIV status; family planning options; gender based violence, sero-discordant relationships; sexual dysfunction, etc.</td>
<td>- Train male peer counsellors and expert clients living with HIV on treatment literacy and adherence so they can provide support to men living with HIV in the clinics and in their own communities.</td>
<td>- Ensure that men and boys understand their roles as sexual partners and each partner’s responsibility to be equally concerned with their own and their partner’s sexual health.</td>
</tr>
<tr>
<td>- Train service providers to address the specific needs of men living with HIV by changing service providers’ values or attitudes towards men and boys accessing SRH care.</td>
<td>- Provide referrals for men to access services (including skills building and employment opportunities) through close working partnerships with other health, social and legal service providers.</td>
<td>- Challenge norms about gender and masculinities by establishing ‘safe spaces’ where participants can reflect on what it means to be a man; developing campaigns and outreach work to promote change and show the benefits this could bring.</td>
</tr>
<tr>
<td>- Promote access to sexual and reproductive health services, including family planning and prevention of mother-to-child transmission by men and boys.</td>
<td></td>
<td>- Provide up to date information to men and boys on possible legal implications of certain behaviours and/or referral to legal assistance organizations.</td>
</tr>
</tbody>
</table>
### MEN WHO HAVE SEX WITH MEN\(^{19}\)

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>- Conduct outreach activities and develop health promotion strategies in hot spots and areas where men meet for sex.</td>
<td>- Provide specific care for other clinical problems in the ano-genital area such as anal fissures.</td>
<td>- Promote a safe and secure environment ensuring protection of men who have sex with men against violence, discrimination or persecution.</td>
</tr>
<tr>
<td>- Promote services for the diagnosis and treatment of oral and rectal infections, HPV and anal cancers.</td>
<td>- Train men who have sex with men as peer counsellors and expert clients on treatment literacy and adherence so they can provide support to men who have sex with men in the clinics and in their own communities.</td>
<td>- Promote changes in legislation or in attitudes or practices that can prevent the provision of essential SRH and HIV services to men who have sex with men.</td>
</tr>
<tr>
<td>- Provide counselling for sexual health problems that give rise to sexual dysfunction, anxiety, psychological problems, etc.</td>
<td>- Reach out to their female partners with sexual and reproductive health services.</td>
<td>- Promote the rights of people in sexual minority groups including the rights to respect and dignity, non-discrimination, equality, participation, life, identity, self-determination and access to health.</td>
</tr>
</tbody>
</table>

\(^{19}\) The term MSM is used to describe any man who has sex with another man, regardless of their sexual identity or gender orientation, and whether or not he also has sex with women.

### PEOPLE WHO USE DRUGS AND THEIR SEXUAL PARTNERS

<table>
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</thead>
<tbody>
<tr>
<td>○ Provide sexual and reproductive health services linked to harm reduction programmes for people who use drugs and their sexual partners.</td>
<td>○ Promote regular monitoring of hepatitis C viral load and ensure timely access to hepatitis C treatment when clinically indicated.</td>
<td>○ Promote a supportive environment in which healthy lifestyles are attractive and achievable.</td>
</tr>
<tr>
<td>○ Conduct outreach activities, mobilize users and distribute IEC materials, clean needles and syringes, condoms and lubricants in hot spots where drug use may take place.</td>
<td>○ Facilitate access to psychosocial support and drug treatment programmes – such as OST, day care programmes, rehabilitation centres, medical heroin prescription, etc.</td>
<td>○ Ensure that interventions to reduce drug demand and HIV prevention programmes are linked to broader social welfare and health promotion policies including poverty reduction and opportunities for education and employment.</td>
</tr>
<tr>
<td>○ Promote peer to peer education strategies to disseminate information about risks associated with the use of amphetamine-type stimulants (ATS) and the increase in risky sexual behaviour.</td>
<td>○ Ensure access to ART according to WHO guidelines for treatment initiation irrespective of lifestyle choices or current drug use patterns.</td>
<td>○ Advocate for the inclusion of harm reduction programmes inside prisons, including needle exchange, OST programmes and timely access to health care including ART, hepatitis and TB treatment.</td>
</tr>
<tr>
<td>○ Facilitate access to PMTCT services for pregnant women who use drugs ensuring appropriate linkages to drug treatment programmes.</td>
<td>○ Facilitate access to OST for people with opioid-based dependency, and other treatment for those using ATS including access to smoking equipment – as this could reduce the frequency of injection.</td>
<td></td>
</tr>
<tr>
<td>○ Provide on-going support to pregnant women who use drugs, involve their partners and ensure mothers and babies stay together in a maternity ward.</td>
<td>○ Be aware of drug interactions, particularly the interactions between ART, TB and hepatitis therapy to ensure correct use and dosage of OST.</td>
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</tr>
<tr>
<td><strong>SEX WORKERS</strong></td>
<td><strong>Protect their sexual and reproductive health</strong></td>
<td><strong>Delay disease progression</strong></td>
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<tr>
<td></td>
<td>Involves sex workers living with HIV in peer education programmes to promote condom use and other safer sex techniques with clients and regular (non-paying) partners.</td>
<td>Promote access to counselling services to address HIV and lifestyle issues in the context of their lives as sex workers living with HIV.</td>
</tr>
<tr>
<td></td>
<td>Ensure the package of SRH services includes the provision of family planning methods, emergency contraceptives and safe abortion services.</td>
<td>Train sex workers living with HIV on treatment literacy and adherence so they can provide support to other sex workers living with HIV in the clinics and in the community.</td>
</tr>
<tr>
<td></td>
<td>Promote routine cervical and breast cancer screening.</td>
<td>Ensure access to appropriate services for the prevention of mother-to-child transmission for pregnant sex workers.</td>
</tr>
<tr>
<td></td>
<td>Ensure access to appropriate services for the prevention of mother-to-child transmission for pregnant sex workers.</td>
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</tbody>
</table>

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20. Female, male and transgender adults and young people who receive money or goods in exchange for sexual services, either regularly or occasionally, and who may or may not consciously define these activities as income generating. Source: UNAIDS. Sex Work and HIV: Technical Update. 2002.
## TRANSGENDERED PEOPLE

<table>
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<tr>
<td>Address the cosmetic needs of transgendered people including access to hormonal supplements, breast and genital reconstruction and facilitate counselling to deal with issues such as expressing their own sexuality.</td>
<td>Facilitate the provision of comprehensive care for gender reassignment, including appropriate use of hormonal therapy.</td>
<td>Promote changes in laws and policies and ensure legal recognition of transgendered people in their own right.</td>
</tr>
<tr>
<td>Promote services for the diagnosis and treatment of oral and rectal infections, HPV and anal cancers.</td>
<td>Provide specific care for clinical problems in the ano-genital area such as anal fissures and HPV.</td>
<td>Promote a safe and secure environment ensuring protection of transgendered people against violence, discrimination or persecution.</td>
</tr>
</tbody>
</table>

### Translated Note

21. It is a term used to describe a population who have changed their sexual identity. Born as males or females, transgendered people adopted the opposite gender identity. Males that adopted a female identity can be identified as “women”, “not-men”, “in-between man and woman”, “neither man nor woman”. The term transgendered cover many identities and behaviour and different cultures use different names for transgendered people, for example hijras in South Asia, transvesti in Latin America or yan dauduin in northern Nigeria. **Source:** Between Men: HIV/STI Prevention for Men Who Have Sex With Men. International HIV/AIDS Alliance. 2003.
### WOMEN AND GIRLS

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</tr>
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<tbody>
<tr>
<td>• Ensure the provision of quality SRH information and services, including family planning, STI, PMTCT and abortion services, to all women living with HIV, irrespective of age or marital status.</td>
<td>• Train female peer counsellors and expert clients living with HIV on treatment literacy and adherence so they can provide support to women and girls living with HIV in the clinics and in their own communities.</td>
<td>• Promote strategies to address HIV related stigma and discrimination and support the establishment of support groups and other strategies that build solidarity among HIV-positive women.</td>
</tr>
<tr>
<td></td>
<td>• Ensure access to appropriate services for planning a safe and healthy pregnancy including information on safe conception, pregnancy and delivery and counselling on infant feeding options.</td>
<td>• Promote safe and protective environments to ensure women and girls are protected against violence.</td>
</tr>
<tr>
<td></td>
<td>• Promote routine cervical and breast cancer screening.</td>
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</tr>
</tbody>
</table>
### YOUNG PEOPLE

<table>
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</thead>
<tbody>
<tr>
<td>- Ensure the inclusion of comprehensive sexuality education(^{22}) for both boys and girls in primary and secondary education, which promotes a positive approach to the sexuality of young people living with HIV.</td>
<td>- Train youth peer counsellors and expert clients living with HIV on treatment literacy and adherence to support young people living with HIV in the clinics and in the communities.</td>
<td>- Ensure that young people understand their roles as sexual partners and each partner’s responsibility to be equally concerned with their own and their partner’s sexual health.</td>
</tr>
<tr>
<td>- Provide information and education to young people living with HIV on safer sex, sexual health and safe pregnancy.</td>
<td>- Provide referrals for young people to access services (including life skills training) through close working partnerships with other health, social and legal service providers.</td>
<td>- Support young people in deciding if, when and how to approach disclosure with sexual partners – this is of particular importance for young people living with HIV as they may not have a long-term sexual partner. Support should address issues around repeat disclosure.</td>
</tr>
<tr>
<td>- Establish youth friendly services in clinics and youth centres to support young people living with HIV to access comprehensive SRH and HIV services, including family planning services and access to emergency contraceptive and abortion services when needed.</td>
<td>- Ensure healthcare providers receive adequate training to care for young people living with HIV, including addressing HIV-related stigma, and understanding their duty to protect client confidentiality.</td>
<td>- Provide up to date information to young people on the possible legal implications of certain behaviours and/or referral to legal assistance organizations.</td>
</tr>
<tr>
<td>- Provide counselling and psychosocial support – through peer-to-peer counselling and support groups – to young people living with HIV to help them deal with issues such as disclosure of HIV status to sexual partners, families and friends; sexuality and sero-discordant relationships.</td>
<td></td>
<td>- Develop strategies to reduce stigma and discrimination experienced by young people living with HIV.</td>
</tr>
</tbody>
</table>

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http://www.ippf.org/NR/rdonlyres/CE7711F7-C0F0-4AF5-A2D5-1E1876C24928/0/Sexuality.pdf
In this section

- Useful resources related to positive prevention
Useful resources related to positive prevention

General related publications

Protecting your sexual and reproductive health and avoiding other sexually transmitted infections (STIs)


Appendix

Delaying disease progression


Promoting shared responsibility to protect your sexual health and reduce the risk of HIV transmission

- Timberlake, S. (April 2009) Links between positive prevention, the legal environment and programmes to empower. Presentation at the International Technical Consultation on “Positive Prevention”, organised by GNP+ and UNAIDS.
Acknowledgements

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IPPF is a signatory of the NGO Code of Good Practice.

Designed by Jane Shepherd.
Published February 2010.
People living with HIV, like those who are HIV negative, play an essential role in preventing new HIV infections. Key approaches for prevention for and by people living with HIV include individual health promotion, access to HIV and sexual and reproductive health services, community participation, advocacy and policy change.