

# Big Issues In Brief

## Scaling up responses to HIV/AIDS

### Living Positively with HIV/AIDS



#### The issue.

In scaling up programs for HIV/AIDS care and treatment, fostering ways to harness the experience, skills, and talents of people who have tested HIV-positive is vital to help them:

- Remain well longer
- Make important plans for their futures and the futures of their families
- Provide psychosocial peer support to others who have tested positive
- Undertake “treatment support” to others on antiretroviral therapy
- Contribute to the effort in their communities to reduce the spread of HIV infection and mitigate its effects on individuals, families, and the community

#### Why is this important?

In order to get two million people onto antiretroviral therapy, it will be necessary to test around 100 million people. On average, 80 percent of people will test negative. Of those who test HIV-positive, up to 90 percent will not yet be at a stage in the progression of their infection to need antiretroviral therapy.<sup>1</sup> Thus, more than 18 million people who are tested will find that they are HIV-positive, but they will not have immediate access to medical treatment. With the policy trend toward opt-out HIV testing—that is, routine HIV testing on presentation to health facilities unless the person “opts out” of being tested—fewer people will receive pretest counseling. Those who test for HIV may not fully understand that while they might test positive, they may not be immediately eligible for treatment. Posttest counselors must ensure that people

The people and organizations highlighted in the shaded boxes in this document were identified in field reports as “success stories.”

who receive a positive test result and who are not immediately eligible for antiretroviral therapy understand the importance of “living positively.”

## **Botswana**

“Knowing our HIV status helped us know exactly what we needed to do. So we took the whole package that the government offers,” said 28-year-old Motse.

Posttest counseling on living positively includes information on reducing the risk of infecting others, on symptoms that would indicate progression of their infection and be cause for the HIV-positive person to return to a health care facility for treatment, and on sources of psychosocial support. Experts agree that psychosocial support, an integral part of HIV counseling, is important to help individuals cope with the distress of a positive HIV test. As there is evidence of increased risk of suicide in HIV-positive males in many countries, including the United States and South Africa, and in Guyana, among those of Indian origin,<sup>2</sup> counseling and support for “living positively” must be provided at the exact time when a positive test result is disclosed. In many settings, women who test positive during antenatal care fear rejection, abuse, and other violence from their partners.<sup>3</sup> Thus, another important component of support for “living positively” is counseling that addresses fears related to disclosure and how one knows when it is safe to disclose.

## **What is known?**

### *The importance of risk-reduction counseling*

Most people who test positive for HIV will remain sexually active after receiving their test results. They need to know how to reduce the risk of passing HIV infection on to others, primarily through adoption of safer sex practices. They also need to know that they should not give blood donations or share razors. Guidance on living positively must stress the importance of proper and consistent use of male or female condoms for sexual intercourse, and information on where condoms are available locally must be stressed. Even if their partners are also HIV-positive, concerns about reinfection or “superinfection” mean that they should adopt or continue safer sex practices.

## **Kenya**

Jemima is a 48-year-old woman living with HIV who cared for eight orphaned grandchildren. Although she became very ill, wasting away with candida infection and pneumonia, her health and strength returned with treatment for her infection, nutritional support, and prophylactic cotrimoxazole to prevent future opportunistic infections.

Once her health improved, Jemima went on to share information about HIV/AIDS care and support with community leaders and others. She promotes point-of-use chlorination and clean-water storage, and she also founded an orphans group that provides emotional support and networking for community fund-raising events. She has established a posttest club and is responsible for referring many people to a patient center that provides care, support, and treatment of opportunistic infections.

## *HIV-positive women*

Because HIV-positive women can pass HIV infection to their infants, they need specific counseling about decisions on future pregnancies and infant feeding. Women who test positive in pregnancy have increased need for support to “live positively” to help them implement behaviors that reduce transmission to their infants. Behaviors may include adoption of safer sex during pregnancy and lactation, taking antiretroviral drugs to reduce transmission during pregnancy and delivery, and either exclusive breastfeeding or exclusive replacement feeding. Such behaviors generally require disclosure to health service staff, the woman’s partner, and even other family members.

## *Disclosure to sexual partners*

Sexual partners of HIV-positive people are at increased risk of becoming HIV-positive. For these partners, knowing their HIV status can be critically important. Some legal and human rights organizations consider disclosure of HIV status to a sexual partner to be a human rights issue and not merely a matter of personal choice. Partners need to know how they can help reduce the risk of infecting unborn and breastfeeding infants. Thus, guidance on HIV-status disclosure, on reducing mother-to-child transmission, and on reducing the risk of infecting others is essential in counseling for “living positively.”

## *Children and other dependents*

All who test positively need to plan for the future. Counseling should cover the areas that require planning, including making provisions for persons to look after minor children and dependent parents. This is called succession planning.<sup>4, 5</sup> As well as identifying guardians, a person who tests HIV-positive needs to consider what will happen to property and how to ensure that one’s wealth benefits his or her children and other dependents. Although traditional practice may prescribe that brothers take responsibility for the dependents of their deceased siblings, traditional mechanisms may be stretched beyond capacity in highly HIV-affected families, or the stigma of HIV/AIDS may lead to a departure from traditional practices. Women and their children are particularly vulnerable to abuse of traditional inheritance practice if they are known or suspected to be HIV-positive. Thus, “living positively” should include preparing a will or other legal procedure for ensuring inheritance of personal property, homes, and land. Parents can also prepare memory books or boxes that contain small heirlooms, notes on family history, personal messages, guidance on rites of passage for their children to have after the parents’ death,<sup>6</sup> and suggestions as to where their children should seek advice on any future problems.

## *General health and nutrition*

Maintaining good general health and nutrition can contribute to maintenance of immune system function. Living positively includes ensuring a healthy, balanced diet, and avoiding sexually transmitted infections and malaria. This is particularly important for pregnant women, as malaria parasite infection of the placenta increases the likelihood of passing HIV to the unborn infant. Thus “living positively” means sleeping under bed nets—preferably treated bed nets—in malarious areas and receiving intermittent presumptive treatment for malaria during pregnancy, even if the pregnant woman does not have symptoms of malaria. Tuberculosis (TB) is a problem for people living with HIV/AIDS. In resource-poor settings, people may be infected with TB without knowing it. The TB bacillus can remain dormant within the body without producing any symptoms of disease. As the immune systems of HIV-positive people are affected by the HIV infection, their CD4 count is reduced, which increases the likelihood that dormant TB can flare up and become active and infectious. The risk of a dormant TB infection flare-up exists even for people who have received BCG

immunization in childhood. Therefore, “living positively” includes recognizing the increased personal risk of TB and seeking medical treatment for coughing *in any member of the household* that lasts for more than three weeks.

### **Cote d’Ivoire**

In the few short years since she learned her HIV-positive status, Semi-Lou has become a leader in her community and a wonderful example of positive living. She founded an HIV support association called “Active Women” that seeks to ensure that HIV-positive women and their families are supported to access comprehensive treatment services that include psychosocial peer support for themselves, their partners, and their larger families. Through Semi-Lou’s dynamism and leadership, “Active Women” has grown to more than 300 members and is a participant in the national network of organizations of people living with HIV/AIDS.

### ***Client recall of posttest counseling sessions***

Even if all aspects of “living positively” are addressed thoroughly in posttest counseling, it is unlikely that the HIV-positive person will remember all that has been discussed. The distress of learning an HIV-positive diagnosis, along with other psychological mechanisms, can be a barrier to good recall. Learning of a positive HIV test result can be followed by denial and anger before acceptance. These emotions can also lead to forgetting posttest counseling. Most importantly, people who test positive need repeated assurance that they can live many years symptom-free and, with treatment, many more years after that. They need reassurance that they can remain in control of their own lives and that they can set in motion preparations to help provide security for their dependents, in order to regain their self-confidence and dignity. One way to ensure that people who have received an HIV-positive result continue to receive guidance and support for “living positively” is to refer them to support organizations in their communities.

### ***Continued psychosocial support in the community***

Posttest clubs, founded by the testing organization, have been found to be beneficial in some settings. People living openly with HIV/AIDS are well placed to provide ongoing assistance to those who test positive, as they have had to address all the “living positively” issues themselves under similar circumstances. In many settings, people living with HIV/AIDS have founded self-help organizations or networks that provide continued support including nutritional support and guidance, economic support—sometimes through small enterprises and skills-building—childcare and other social services, as well as counseling group psychological support. Psychosocial support mechanisms will vary across communities and even within a community. An urban mother may value someone who can look after her children for a few hours each week, whereas a rural mother may value assistance with her kitchen garden. A human capacity development (HCD) approach can facilitate a strong community response to HIV/AIDS, strengthening locally appropriate support mechanisms. This is preferable to decisions by outsiders on support services, and this may encourage community members to come forward for training as counselors, guidance workers, or HIV-prevention motivators. Experience with the HCD approach has demonstrated increased demand for HIV testing in some settings, even where antiretroviral therapy is not yet available.<sup>7</sup>

## *Networks and organizations of people living with HIV/AIDS*

Membership in organizations of people living with HIV/AIDS or those affected by HIV/AIDS can give a sense of purpose, as well as shared adversity, providing peer support to each other, and prevention and mitigation service to the wider community. There are numerous examples, such as The AIDS Support Organization (TASO) in Uganda, an early community response organization founded by volunteers in 1987.<sup>8</sup> Most TASO workers are people living with HIV/AIDS, and they know they may not have long to live. TASO, however, is not pervaded by gloom and despair. It is an organization where there is laughter, good humor, and infectious enthusiasm, and where there is always a sympathetic ear or a shoulder to cry on if needed. TASO's workers have an overwhelmingly positive approach, embodying the organization's commitment to "living positively."

### **Guyana**

Brenda, a 25-year-old mother, was tested for HIV at her first antenatal visit during her second pregnancy. She experienced different emotions when she learned that she was HIV-positive: first disbelief, then hurt. The health workers reassured her that she could live a healthy life with HIV. Brenda told her mother and siblings, who experienced grief but who provided the psychosocial support she needed to get through the program on prevention of mother-to-child transmission, in which she received further counseling on infant feeding and safe sex, as well as family planning. Brenda and her infant received nevirapine prophylaxis, and her baby remains HIV-negative. After giving birth, she became an advocate and community educator for the Network of People Living with HIV/AIDS. "Today, I can use myself as an example to talk to other women about HIV/AIDS," said Brenda. "I am not ashamed of my condition and feel that I can use my experience to help others."

Those who test HIV-positive need to obtain treatment for sexually transmitted infections, TB, and other opportunistic infections, and for malaria in malarious areas as their infection progresses. Thus, it is important that those who test positive be tracked by the health services. Keeping in touch with those who test positive is increasingly important now that treatment is becoming more available through scaled-up health provision programs. Yet health services in resource-poor settings are not set up to track care and treatment for people who have chronic conditions such as HIV/AIDS. Most health services in resource-poor settings are organized around provision of treatment for acute conditions that do not require long-term tracking of patients and their treatment. Mother and child health services typically provide care for women during pregnancy and delivery, and for their children up to age five, and avoid the issue of long-term patient tracking and treatments—especially childhood immunizations—through the use of patient-held records. Until mechanisms are established for tracking people who have tested HIV-positive, voluntary self-identification of people living with HIV through membership in groups such as TASO can potentially provide the essential link to future access to health care and treatment. Good nutrition and healthy lifestyle choices prolong good health and productive life, but such changes demand more than individual behavior change. They require the encouragement of peers and the wider society. This encouragement is another important function of group like TASO.

## Good and promising practice

Large and long-established organizations such as TASO are acknowledged models of best practice. But there are many more often unsung heroes and heroines of small, local organizations that provide psychosocial and other assistance to people living with HIV/AIDS in communities affected by the epidemic. Good practice is to identify and enable organizations that can fill these important roles in the promotion of “living positively” as efforts expand to scale up prevention of mother-to-child transmission, and care and treatment of those with AIDS. During the final three months of pregnancy, mothers in Mozambique are encouraged to attend a “positive mothers group” that is part of the health center program on preventing mother-to-child transmission. During weekly meetings, HIV-positive pregnant women receive information and counseling on establishing exclusive optimal breastfeeding (soon after delivery until about six months), nutrition, preparation of complementary food for their infants, and the need to address the social pressures of living with HIV. Interventions to reduce stigma, prevent new infections, and stress the importance of partner testing should also be included in “living positively” programs.

### Rwanda

“I’m ready for every occurrence, as long as I can increase my life by a few or many years, because my three young children need me. Even the ones who are married still need me.

I am just thankful to the program that gives me free medication [antiretroviral therapy]. I can come back to work now that I feel strong again, starting with maybe two days a week, and then increasing the number of days, depending on my strength. Also, I want to advise other people who have AIDS not to despair, but to be strong and have hope. If necessary, I will give them testimony on how the medication helped me. I will tell them that my life is going on, and how grateful I am toward the health center and toward God, who is working miracles for me.”

## Challenges

### *Stigma*

The stigma surrounding HIV/AIDS is an all-pervasive challenge<sup>9</sup> that can be exacerbated by both intentional and unintentional behaviors of health care staff and health service record keeping. Rejection of people who are HIV-positive or are perceived to be HIV-positive occurs within couples, extended families, communities, workplaces, health care settings, and at international borders. Experiencing such discrimination can be devastating—emotionally, socially, financially, and physically. Experience in many settings shows that health care workers—even those who have had training as counselors—experience personal difficulty in giving a positive HIV test result. They may mark medical records as HIV-positive or with a symbol that is known to mean HIV-positive, or they may pass the responsibility for giving the test result to another person. This is best addressed by setting performance standards, and linking supervision and performance to rewards. Self-stigmatization by a person infected with HIV is a further challenge to “living positively.” Paradoxically, this is best addressed by interaction and guidance from peers who are living positively with HIV/AIDS.

## *Involving faith-based organizations*

Although some government health services and health facility-based staff may not be well placed to provide ongoing psychosocial care and support in the community, some have the advantage of penetrating deep into the fabric of community life and are able to draw on their mission for compassion to provide support in the community. Nevertheless, enabling people to “live positively” can be a challenge to organizations with a culture of pity for the poor, the unfortunate, and those who have “sinned.” However, as staff of faith-based organizations become affected by HIV/AIDS—either personally or through their family or close friends—leaders and pastors such as Reverend Gideon Byamugisha of Uganda are transforming their perspective and becoming advocates for prevention and role models for living positively with HIV.<sup>10</sup>

### **Zambia**

Ida was diagnosed positive in 2002. She is able to testify to the benefits of antiretroviral therapies and the importance of having support to cope. On a personal level, she talks candidly about her “down days,” when she thinks of [HIV/AIDS] as something that has become who she is. But mostly she lives a very positive life. She even has future plans for herself and for her children, and she knows that if anything happens to her she will be able to take treatment and get back to life.

## *Addressing the needs of those not ready to disclose*

The process of networking and sharing experience has served as powerful therapy for individuals, families, and communities; it has also provided the energy for promoting effective and appropriate national responses. Groups of people living with HIV/AIDS worldwide have been at the forefront of prevention, care, and leadership, strengthening efforts locally, nationally, and internationally. Yet not everyone who is newly identified as HIV-positive wants to be associated with publicity and advocacy efforts. The challenge for many organizations of people living with or affected by HIV/AIDS is harnessing their strength for catalyzing appropriate responses to the epidemic while still providing local, individual, and family care and support for those who are not ready to announce to their wider communities that they are HIV-positive.

## **Links**

UNAIDS. 1999. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. Geneva: UNAIDS. Available at:

<http://www.unaids.org/en/about+unaids/partnerships/partnerships+resources.asp>

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## **Endnotes**

<sup>1</sup> Barbiero, V.K. 2003. “Child Survival and Health Grants: Program Update on HIV/AIDS Prevention and Control.” Unpublished PowerPoint presentation, September 8, 2003. Washington, D.C.: USAID/Office of HIV/AIDS

<sup>2</sup> Cote, T.R., R.J. Biggar, and A.L. Dannenberg. 1992. “Risk of Suicide among Persons with AIDS: A National Assessment.” *JAMA*. 268(15):2066–2068; Meel, B.L. “Suicide and HIV/AIDS in Transkei, South Africa.” *Anil*

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<sup>3</sup> USAID/The Synergy Project. 2004. *Women’s Experience with HIV Serodisclosure in Africa: Implications for VCT and PMTCT*. Washington, D.C.: Social and Scientific Systems, Inc.

<sup>4</sup> Horizons. 2003. *Succession Planning in Uganda: Early Outreach for AIDS-Affected Children and Their Families*. Washington, D.C.: Population Council. Available at: <http://www.popcouncil.org/pdfs/horizons/orphanssum.pdf>

<sup>5</sup> USAID. 2003. “Success Stories HIV/AIDS: Helping HIV-Positive Parents Plan for Their Children’s Futures.” Washington, D.C.: USAID/GBH. Available at: [http://www.usaid.gov/our\\_work/global\\_health/aids/News/successpdfs/ugandastory.pdf](http://www.usaid.gov/our_work/global_health/aids/News/successpdfs/ugandastory.pdf)

<sup>6</sup> Smith, C.L., and R. O’Brine. 2000. *Memory book for Africa*. St. Albans, United Kingdom: Teaching Aids at Low Cost (TALC).

<sup>7</sup> Lucas, S. (in press). *Community, care, change and hope: Local responses to HIV in Zambia*. Washington, D.C.: Social and Scientific Systems, Inc./The Synergy Project.

<sup>8</sup> Hampton, J. 1990. “Living Positively with AIDS: The AIDS Support Organization (TASO), Uganda.” Series for Hope No. 2. London: ActionAid.

<sup>9</sup> The Synergy Project. 2004. *Big Issues in Brief: Stigma and HIV/AIDS—A Pervasive Issue*. Washington, D.C.: Social and Scientific Systems, Inc.

<sup>10</sup> Mande, W.M. 1999. *Positive Living: The Life, Work, and Writings of the Reverent Gideon Byamugisha*. Public lecture at New Synod Hall, Namirembe Diocese, Church of Uganda. August 29, 1999.