



Meaningful Involvement of People Living with HIV/AIDS

The United States is a signatory to the Paris Declaration of 1994, which outlines broad principles for the United Nations initiative on Greater Involvement of People Living with HIV and AIDS in programs that affect their lives.

In countries around the world, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) is putting these principles into practice, by actively engaging people living with HIV and AIDS (PLWHA) in planning for, delivering and monitoring the effectiveness of prevention, treatment and care services. PEPFAR country teams consult with national networks of PLWHA to help determine priorities for annual operational plans, and to involve PLWHA in programming and efforts to assess program responsiveness.

Programs support by PEPFAR recognize PLWHA as:

- Vital contributors to the success of prevention efforts;
- Important partners in health care delivery;
- Sources of care and support for their communities; and
- Effective advocates who can help build in-country capacity, local ownership, and accountability to promote sustainable efforts.

Prevention with Positives

In many developing countries, those at highest risk for HIV infection are the uninfected sexual partners of people who are HIV-positive. Therefore, PEPFAR treatment and care programs are rapidly incorporating "Prevention with Positives" interventions that support PLWHA in reducing new HIV infections. Other prevention programs involve PLWHA in prevention programming as spokespeople to discuss the often difficult realities of living with HIV/AIDS.

Most developing countries are years away from having enough trained health workers to meet all the needs of their nations' health systems. PEPFAR programs are exploring novel approaches that draw on the contributions PLWHA can make in caring for themselves and members of their families and communities.

Programs employ PLWHA to conduct home visits, monitor weight gain and other signs of improving health, look for emerging health problems, and deliver prescription refills to people on antiretroviral treatment. This approach not only provides meaningful paid work for PLWHA, but also helps decongest crowded health facilities, lower the number of facility-based health workers needed, and reduce travel burdens and associated costs for patients.

The U.S. President's Emergency Plan for AIDS Relief is the largest commitment ever by any nation for an international health initiative dedicated to a single disease.

U.S. Department of State

U.S. Agency for International Development

U.S. Department of Defense

U.S. Department of Commerce

U.S. Department of Labor

U.S. Department of Health and Human Services

Peace Corps

**Mailing address:
SA-29, 2nd Floor
2201 C Street, NW
Washington, DC 20522-2920
www.PEPFAR.gov**



PEPFAR at Work

The following examples are representative of PEPFAR's efforts to support the active and meaningful involvement of PLWHA:

- **In South Africa**, the Mothers to Mothers-to-Be program employs, trains and supports HIV-positive women who have received prevention of mother-to-child HIV transmission (PMTCT) interventions. These women educate pregnant, HIV-positive women about PMTCT. Through the program, women learn the importance of knowing their HIV status, how to access PMTCT programs, steps to prevent mother-to-child HIV transmission, and how they can benefit from the social support of other HIV-positive people.
- **In Kenya**, PEPFAR supports a number of efforts to link PLWHA who have similar interests. For example, in one network, HIV-positive educators provide care for their network's members and work to improve Kenya's educational environment. In other networks, HIV-positive religious leaders, Muslim women and disabled people provide a similar supportive environment for their network's members within the community.
- **In Mexico**, a group of multinational corporations joined forces to launch a national business council in Mexico, called Consejo Nacional Empresarial Sobre SIDA (CONAES), on World AIDS Day 2004. The council was formed to identify the most difficult problem facing Mexico concerning HIV/AIDS – pervasive stigma and discrimination against PLWHA. In its first year, CONAES recruited more than 20 large, multinational companies to join the council, and also sponsored a conference on HIV/AIDS in the workplace. As members, companies commit human and financial resources to fighting discrimination against PLWHA in the workplace.
- **In Nepal**, a group of 15 Nepalese women founded Sneha Samaj, the first support group for women and children living with or affected by HIV/AIDS. Sneha Samaj means “community for love and affection.” The organization received start-up money to open a shop as an income-generating endeavor. With the funds, they purchased six sewing machines, sewing tables, racks, irons, scissors and lights, and employed seven women. Profits from the sale of products go toward Sneha Samaj's treatment and care programs.
- **In Côte d'Ivoire**, RIP+ is an association of groups of PLWHA that employs integrated and comprehensive programming, building the capacity of local organizations to provide care and support to people living with HIV/AIDS. RIP+ received a PEPFAR New Partners Initiative grant on World AIDS Day 2006 to provide HIV counseling and testing, palliative care, and care for orphans and vulnerable children, as well as prevention programs using the ABC approach.

Resources:

The U.S. Government supports publication of regional and international directories of associations of people living with AIDS. Current directories are available at www.usaid.gov/our_work/global_health/aids/Publications/index.html. The U.S.-based National Association of People with HIV/AIDS (NAPWA, www.napwa.org) and the Global Network of People Living with HIV/AIDS (GNP+, www.gnpplus.net) are frequently involved in program planning, implementation and assessment.