

## Partnerships with people living with HIV

### People living with HIV - key partners

33.3 million men, women and children were estimated to be living with HIV in 2009. People living with HIV often understand each other's situation better than anyone else and are well placed to educate, counsel and advise one another. Around the world, wherever HIV is present, people living with HIV have established support and advocacy groups and networks. Increasingly, members of the groups have been successful in their demands to be included in decision and policy making forums.

Since AIDS emerged, people living with HIV have been a key driving force in the response and few of the advances made in the last 25 years would have happened without the tremendous efforts, expertise and advocacy of people living with HIV and affected communities. With appropriate support, people living with HIV can and must take a central role in their own country, region, or locality in the design, implementation, monitoring and evaluation of AIDS programmes. Their involvement gives personal power and immediacy to AIDS efforts, improves the technical elements and relevance of programmes, enabling buy-in by the broader people living with HIV constituency and the community in general and inspiring others into action.

### Greater involvement of people living with HIV (GIPA)

The idea that the personal experiences of people living with HIV could and should be translated into helping to shape a response to the HIV epidemic was first voiced in 1983 at a national AIDS conference in the USA through "The Denver Principles". It was formally adopted as a principle at the Paris AIDS Summit in 1994, where 42 countries declared the Greater Involvement of People Living with HIV and AIDS (GIPA) to be critical to ethical and effective national responses to the epidemic.

Today the principle of greater and meaningful involvement of people living with HIV is central to many interventions worldwide, people living with HIV are involved in a wide variety of activities at all levels of the AIDS response; from supporting others locally through counseling and treatment literacy initiatives to service provision and participating in major national, regional and global decision and policy-making activities.

The engagement of people living with HIV and key affected populations is all the more urgent as countries scale up their national AIDS responses to achieve the goal of universal access to prevention, treatment, care and support services.

### UNAIDS GIPA Policy Position

No single partner can provide for the full spectrum of needs of people living with HIV: partnerships between actors are therefore needed. To enable the active engagement of



people living with HIV, UNAIDS urges all actors to ensure that people living with HIV have the space and the practical support for their greater and more meaningful involvement.

Governments, international agencies and civil society must:

- set, implement and monitor minimum targets for the participation of people living with HIV, including women, young people and marginalized populations, in decision-making bodies. Selection processes should be inclusive, transparent and democratic; and
- involve people living with HIV in developing funding priorities and in the choice, design, implementation, monitoring and evaluation of HIV programmes from their inception.

### **Capacity Building and organizational development**

There is still much to be done to maximize the participation of people living with HIV in the AIDS response. One crucial aspect is the need to support the capacity building and organizational development of groups and networks of people living with HIV and ensure they continue to be financially supported to engage in their work. This is essential if they are to participate fully in the response and properly represent the needs of their constituencies. Capacity building can include assistance for strategic planning and to build organizational, managerial, programmatic, communications, technical and financial expertise within the organization.

### **Addressing stigma, discrimination and human rights**

Tackling the stigma and discrimination, discriminatory policies and laws and violations of human rights experienced by people living with HIV and key affected communities is fundamental to creating an environment for meaningful contribution as partners in the AIDS response. In order to challenge and overcome stigma and discrimination, combat policies and laws that block an effective AIDS response, and to protect human rights, efforts should be undertaken to monitor and document when, where and how human rights violations are taking place. Tools such as the PLHIV Stigma Index, the Human Rights Count and the Criminalization Scan are key to scaling up these efforts and are an important step towards putting in place effective anti-stigma programming and protecting the rights of communities living with and affected by HIV.

### **Advocacy**

To ensure the greater and meaningful involvement of people living with HIV in the AIDS response, UNAIDS works closely with key networks of people living with HIV at global level. They include the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women living with HIV/AIDS (ICW) and the International Treatment Preparedness Coalition (ITPC). Work with all organizations includes a focus on the urgent need to secure increased active participation of people living with HIV in key global, regional and national decision making forums. At country level, all UNAIDS country offices are actively supporting national and regional organisations and networks of people living with HIV through a wide range of activities.

## **Positive Health, Dignity and Prevention**

Positive Health, Dignity and Prevention is an umbrella under which UNAIDS activities to partner with people living with HIV organizations fall. It involves a supportive legal and policy environment and a focus on holistic health promotion - not only on prevention of HIV transmission. It is tailored to setting, to key populations and to the individual, and is defined by people living with HIV.

At a GNP+ and UNAIDS International Technical Consultation on 'Positive Prevention' in Tunisia in April 2009, networks of people living with HIV, civil society organisations, country programme implementers, as well as development, multilateral, UN and donor agencies met to develop the concept of 'Positive Health, Dignity and Prevention' and define its principles.

### **Key aspects of Positive Health, Dignity and Prevention:**

- Requires a supportive and protective legal and policy environment free of stigma and discrimination
- Should promote holistic health and wellness, including equitable access to voluntary HIV testing, treatment, care and support services
- Must improve and maintain the health and wellbeing of people living with HIV, which, in turn, contributes to the health and wellbeing of their partners, families and communities
- Should include addressing psychosocial, economic, educational and socio-cultural vulnerabilities, gender and sexuality
- Should be responsive to the needs of key populations and should respect and be tailored to specific contexts and the diversity among people living with HIV

### **Values and Principles of positive Health, Dignity and Prevention:**

- People living with HIV must be leaders in the design, programming, implementation, research, monitoring and evaluation of all programmes and policies affecting us.
- A human rights approach is the foundation of Positive Health, Dignity and Prevention
- Preventing HIV transmission is a shared responsibility of all individuals irrespective of HIV status
- Sexual and reproductive health and rights must be recognized and exercised by everyone regardless of HIV status