

What is community engagement?

The International HIV/AIDS Alliance has a comprehensive approach to HIV prevention, treatment, care and support for adults and children living with and affected by HIV. The Alliance calls this approach **Community Engagement**.

This means bringing people with HIV, community stakeholders and health providers together to develop partnerships, address gaps and difficulties, and support families and individuals. Each has different roles to play in the community engagement process, which builds on their experience and strengths and coordinates their activities to achieve the following aims:

- Mitigating the impact of stigma and discrimination on HIV prevention, treatment, care, and support
- Increasing community awareness and understanding of available HIV services
- Increasing access to and use of services through referral systems and support
- Increasing community awareness and understanding of the connections between prevention, care and treatment
- Supporting individuals in successful use of treatment and preventive behaviours
- Supporting health care workers in delivering services and ensuring that their own health needs are met.

Who should be involved in community engagement?

Key stakeholders should be chosen with gender balance in mind, and will typically include:

- Local health centre and HIV clinic staff
- Networks of positive people including children and young people affected by HIV
- Networks of marginalised groups (such as sex workers)
- Local decision-makers (such as councils and health committees)
- Home based care providers
- Youth leaders and young people themselves,
- School teachers and parents' representatives
- Traditional leaders, educators and healers
- Pastors and others with moral and spiritual influence in the community
- Local employers, and businesses such as pharmacies.

What are the components of community engagement?

Community engagement depends on:

- Local action developed by those who are familiar with the challenges and strengths in each community
- Positive people's involvement as key informants, planners and implementers
- Linkages between community structures and health system
- A two-way referral system that ensures people access appropriate services and are followed up and supported within the community
- Community education and treatment preparedness
- Linkages to other forms of support when needed – such as food & nutrition, economic strengthening, family planning, child survival etc (sometimes called 'wrap-around' support)
- Developing skills, partnership and knowledge through capacity-building
- Understanding how decisions are made and resources are allocated in the community.

Why is community engagement so necessary?

Despite over 30 years of attempting to slow the HIV epidemic and stop people dying of AIDS, experience shows that in many parts of the world

- not enough people choose to or are able to get tested for HIV,
- safer sex and other prevention measures are neglected
- too few adults and children are benefiting from ARV treatment,
- too few pregnant women are able to use short course ARV treatment to prevent mother-to-child HIV transmission (pMTCT) and too many children are born with HIV,
- people with HIV experience stigma, discrimination and violations of their human rights
- resources are not always allocated to those that need them most

It remains essential to strengthen and scale up health services for HIV prevention and care. However, it is also clear that many of the important barriers which interrupt or prevent good treatment, care and prevention arise in communities and at home, and need to be addressed in those contexts, for example:

- Stigma, secrecy, fear of disclosure
- Gender, age and power imbalances which affect sexual relationships, prevention and access to treatment
- Myths, misunderstanding and fears about HIV, prevention and treatment
- Long distances from home to clinics and support services
- Poverty and lack of money for:
 - drugs, laboratory tests and condoms (if these are not provided free of charge)
 - costs of attending clinics – transport, food, time lost from work
 - meeting other needs of oneself and family e.g. food, education, clothing
- Poor access to individuals and groups that make local decisions about services and resources

These barriers are mostly beyond the reach or resources of health providers. Changing the situation depends on acting with the help of those who live and work in the community. Coordinated action between health care workers and people living with HIV, community leaders and other support providers, will provide a much better possibility of reaching the goals of universal access to prevention, treatment, care and support for all who need it.

How does community engagement work in practice?

In **Zambia** the ACER project has pioneered the Alliance approach since 2004. A referral system operates between home-based care providers, positive people's networks, traditional healers, youth groups and ARV and health clinics. Treatment supporters, openly living with HIV, work in ARV clinics and coordinate partner activities in the community. This has encouraged high levels of treatment adherence, low drop-out rates and reduced stigma.

In **Uganda** the Alliance Networks Support Project has scaled up the approach, with over 80 openly HIV-positive support agents providing adherence support in clinics and communities. They operate a referral system with stakeholders to identify those in need of care and support, linking them to appropriate services and providing ongoing support. Local networks of people with HIV also link with other services for care, food and economic strengthening.

In the **Caribbean** the Alliance supports peer groups of people with HIV to use community engagement tools to develop a dialogue with health providers, leading to reduction in stigma and significant improvements in the quality of health care. This in turn has helped to mitigate the effects of stigma and improve community perceptions of people with HIV.

The **community engagement approach** continues to be applied and developed by the Alliance in these and many other countries and is being adopted by other civil society and public health providers who have experienced its effectiveness in action.