

Policy Briefing No.2

Participation and empowerment in HIV/AIDS programming



Many organisations now understand that participation and empowerment in HIV/AIDS programming is important. This briefing provides an overview of the many lessons that the Alliance and its partners have learned about participation and empowerment in HIV/AIDS work.

The International HIV/AIDS Alliance (the Alliance) is an international non-governmental organisation that supports communities in developing countries to make a significant contribution to HIV prevention, AIDS care and support to children affected by the epidemic. Since its establishment in 1993, the Alliance has provided financial and technical support to NGOs and CBOs from more than 40 countries. In addition, the Alliance promotes good practice in community responses to AIDS more broadly through evaluation, operations research, the development of training materials and tools, as well as policy and advocacy activities.

Key messages

- Meaningful participation and empowerment of affected populations in HIV/AIDS programming increases the impact of prevention and care interventions.
- The participation of those most affected by the epidemic should be promoted at every level of the response and at every stage of programming.
- It is useful to locate participation strategies on a continuum of participation from inclusion through to empowerment, and to be transparent about levels of participation, particularly with regard to the expectations of participants.
- Investing in building an enabling environment that is conducive to prevention and care efforts and also to participation itself strengthens the process of empowerment.
- Participation requires an investment in the development of appropriate skills, attitudes and behaviours of facilitators. NGOs and NGO support organisations are in a strong position to support participation of communities in responding to HIV/AIDS. The provision of technical and financial support for this is important.
- Visual tools help people to communicate better about sensitive issues related to HIV/AIDS, to analyse these issues and to develop appropriate responses.

What is participation and empowerment in HIV/AIDS programming?

Global experience has shown that the effectiveness of responses to HIV/AIDS is strengthened by involving those most affected. In relation to HIV/AIDS programming, this includes involvement in analysing their own vulnerability and risk, in designing projects and in making decisions about interventions. An approach based on real needs ensures that resources are used more effectively and sustainably and ownership of projects is thereby strengthened.

Participation in HIV/AIDS programming is understood by the Alliance to be a dynamic, facilitated process that helps people to actively influence and engage in effective responses to HIV/AIDS. Participatory approaches can build people's skills and confidence, particularly those most stigmatised by the epidemic, increasing their ability to make informed choices. These approaches can also strengthen

service provision and influence the wider environment by helping to confront power dynamics, addressing areas of conflict and reducing stigma through challenging community norms and promoting changes in attitude.

Empowerment can result from participation when those key to the epidemic have sufficient skills, knowledge, confidence, power, self-worth and peer support to make the changes necessary for effective prevention and care – for and by themselves. Empowerment in HIV/AIDS is understood by the Alliance to be a process whereby individuals and communities increase their awareness of HIV/AIDS, their desire and ability to reduce the risk of HIV transmission, and their demand for relevant services and commodities. For example, collective sex worker solidarity strengthens the ability of individual sex workers to negotiate with clients to increase condom use and non-penetrative services. Over the years, the Alliance's experience shows that increased empowerment reduces risk of HIV infection and improves access to AIDS care.

The continuum of participation and empowerment in HIV/AIDS programming

Depending on the need and the context, HIV/AIDS programming lies on a continuum that ranges from telling people what they should do through to inviting active participation in decision making and promoting empowerment and people's ability to determine their own lives.

As organisations move along this continuum in their programming strategies, the impact of their approach will vary depending on the type of participation promoted. It is important to acknowledge the types of participation adopted and to be transparent about why they have been chosen, particularly with reference to the expectations of participants. For higher levels of effectiveness, programming should aim for greater levels of participation.

Participation of people living with HIV/AIDS in NGO and CBO activities: the Horizons/Alliance global operations research study

There are many different ways of representing participation and empowerment. One example is highlighted by the Horizons/Alliance global operations research study in Burkina Faso, Ecuador, India and Zambia. This study explored how the involvement of people living with HIV/AIDS (PLHA) in the delivery of prevention, care and support services at the community

level can contribute to improving the quality of life of people infected and affected by HIV/AIDS.

As well as showing that their involvement can lead to more effective responses, a key outcome from this study was that the process of involving PLHAs in NGO and CBO activities lies on a continuum. It also found that PLHAs need to identify the most appropriate type of involvement actively for themselves, and that NGOs and CBOs need to create conditions to ensure that involvement is meaningful and effective.

Continuum of PLHA involvement (adapted from the Horizons/Alliance study)

Access

Empowerment

PLHA take part in NGO activities as service users. NGO experience of providing services that aim to empower PLHA, such as counselling, life skills and positive living training, indicates that access can be a starting point for further involvement.

PLHA are service users, and are also employed as support staff in non-HIV/AIDS activities or act as 'aides' to service delivery on an informal, occasional, voluntary basis. Examples include non-HIV/AIDS tasks such as gardening, cooking and providing support for HIV/AIDS-related activities, such as informal peer support, testifying and participating in outreach education, drawing on their personal experience of living with HIV/AIDS.

PLHA also deliver HIV/AIDS-related services on a formal, regular basis. As service providers, their expertise is officially recognised by the NGO and they usually receive financial compensation for their work. PLHA may be involved directly in planning the services they deliver and may also be consulted about other services.

PLHA also take part in management, policy making and strategic planning as directors, trustees or programme managers. In addition to making organisational and programmatic decisions, PLHA may also represent the NGO externally.

Promoting participation throughout the stages of HIV/AIDS programming

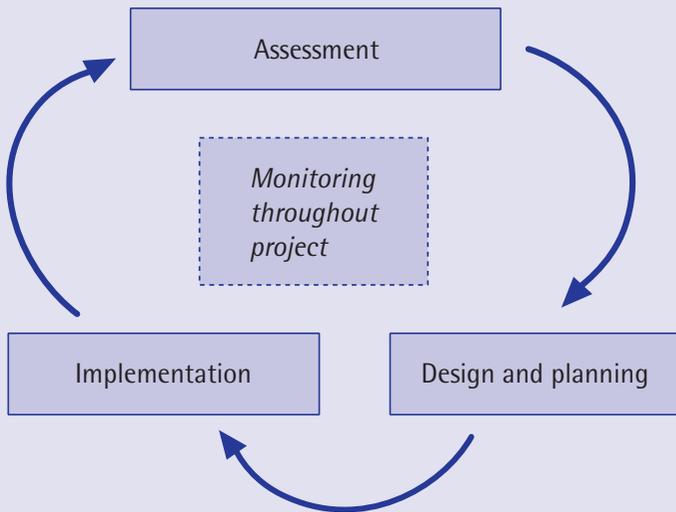
'[The] plan of action to fight AIDS...has been designed from start to finish by us, the men, women and children of this village, ourselves. We have designed it using our own ideas, our own words, in our own language but also within our own limits. It reflects our true needs and recognises our own capacities.'

Member of the Rural Community of Thiennaba, Senegal.

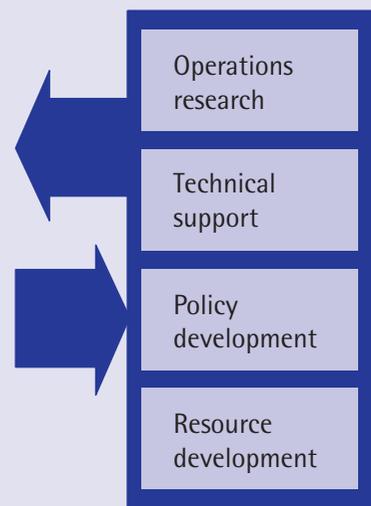
The Alliance promotes the participation of those most affected by the epidemic throughout the project cycle, from needs assessment through to project design, implementation, monitoring and evaluation. Participation is also promoted at an organisational level, in operations research, technical support, policy development and resource development, which feed into and out of the project level participation.

Participation in HIV/AIDS programming

Project level participation



Organisational level participation



As an example of project level participation, participatory community assessments (PCA) are widely used jointly by Alliance partners and affected communities to develop effective project strategies. PCAs support community members in assessing the local context, identifying resources and needs, and making decisions collectively about how to achieve change. The process helps all those involved (e.g. project staff, vulnerable groups, community leaders) to develop an understanding of behaviours, attitudes, services and

community norms and values that influence vulnerability to HIV. PCAs also help to prioritise problems, catalyse individual and group responses to the epidemic and build partnerships between different actors.

In order to carry out effective PCAs with those most marginalised, it is necessary to identify the relevant groups successfully and then create safe spaces where they feel empowered to participate without fear of discrimination from the wider community.

Effectiveness of PCAs: injecting drug users in the Ukraine

In 2001, partners of the Alliance in Ukraine, along with community members and drug users themselves, carried out 20 participatory community assessments across the Ukraine. They looked mainly at HIV vulnerability and injecting drug-related harm. A number of crucial outcomes can be attributed to this process.

- The use of participatory tools increased understanding of the vulnerability of communities, and specifically injecting drug users, including the identification of new vulnerable groups.
- As a result of the assessments, many NGOs adjusted their services in order to meet the needs of their clients better, including by expanding into rural areas.
- Relationships between drug users, the wider community and NGOs improved, resulting in an increase in volunteers from such groups.
- The assessment process resulted in a high level of community mobilisation, with self-help groups officially registering, securing premises and funding and establishing one of the first harm-reduction programmes in Kiev.

Beyond the project level, an example of participation in resource development is *Making Sex Work Safe*. In partnership with the Asia Network of Sex Work Projects, the Alliance is currently supporting groups of sex workers from six countries to adapt the form and content of the publication *Making Sex Work Safe for*

Asian Sex Workers. This includes assessing a wide range of subjects including legal issues, cultural activities and strategies to make sex work safer and reduce drug-related harm. This will be packaged as a multimedia resource that will facilitate further adaptation to local contexts and languages.

Participatory tools and techniques for HIV/AIDS programming

The use of participatory tools and techniques for HIV/AIDS programming can be particularly effective in stimulating discussion of what can be sensitive issues around sexual health and stigmatised behaviours, such as injecting drug use, sex work and men having sex with men. They provide an opportunity to discuss behaviours and norms that influence vulnerability, raise awareness of HIV/AIDS, challenge myths and identify solutions and strategies that may work within particular contexts.

Examples of participatory tools used by the Alliance and partners include: community mapping, seasonal calendars, body mapping, timelines and trends, evaluation wheels, matrix ranking, daily activity charts, cartoon strips, Venn diagrams, causal impact diagrams, problem trees, and network diagrams.

Visual tools can be used very flexibly in order to accommodate the different perceptions and skills of the group. Local materials that are familiar to participants, such as sticks, leaves and stones, can be used to make quite complex drawings and diagrams on the ground, providing a less threatening approach and allowing activities to take place wherever participants live and work or wherever they feel most confident. Visual representations enable ideas and concepts to be expressed so that situations can be thoroughly analysed and different solutions tested for effectiveness. They can also act as records for analysis of change over time.

Using tools for group work enables people to participate to the level and extent of their choice and means that discussions do not have to focus on individuals or individual behaviours. For example, drawing body maps and lifelines for 'typical people' minimises the need for participants' personal disclosures, such as their HIV status, sexuality and risk behaviours.



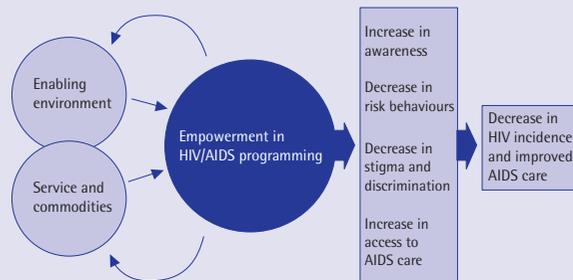
A participant at a workshop in Morocco feeding back from a body mapping exercise.

It is important to note that while the use of participatory tools and techniques helps facilitate the participatory process, they are only one element of this process.

Strengthening the process of empowerment by building an enabling environment

Many of the factors that influence vulnerability to HIV and the ability to take action on HIV prevention, AIDS care and impact mitigation are related to external factors that need to be addressed to enable effective responses. These factors include policy, legal and human rights issues, and the availability of services and commodities such as condoms and voluntary testing and counselling. The synergies between promoting this 'enabling environment' and the empowerment of people affected by the epidemic are mutually reinforcing. For example, as stigma decreases, people with HIV are able to become more visible and advocate for their rights.

Framework showing the links between empowerment and the external environment



However, there is a tension between empowerment as a long-term development approach and the need to respond urgently to the epidemic. To speed and scale up responses at the community level, the Alliance provides technical and financial support to NGOs, CBOs and PLHA groups to help in the empowerment of marginalised groups, providing access to services, resources and commodities and building an environment conducive to prevention, care and support. External or national contexts will affect how quickly an organisation is able to adopt a culture of participation. In some countries the practice of participation can threaten established structures and be risky for the organisation and communities involved. It is important, therefore, to create first a level of acceptance for this type of work to avoid any increased risk for stigmatised groups.