

Extract from: “Community-Based Responses to HIV and AIDS in Uganda: A Review of Irish Missionary Resource Service-supported work”

- 2007 Report by Mary Myaya

Section 2. Community based responses to HIV and AIDS

Best practice in community responses to HIV prevention, treatment, care and support

This section aims to give an overview of appropriate community level responses to HIV and AIDS as requested in the terms of reference. The literature on the subject is vast. This section is aimed at a non-specialist reader and is necessarily broad-brush. It focuses on the components that are included in the responses by partners visited in Uganda, and excludes a description of components that are not the focus of their work (e.g. prevention of intravenous drug use). While it can be argued that governments should be responsible for basic services, particularly clinical services for HIV and AIDS, the reality is that civil society organisations (CSOs) are engaged in all aspects of a community response to HIV.

The most traditional educational messages for **prevention of sexual transmission of HIV** are based on the ‘ABC’ message: Abstain, Be faithful, and use Condoms. The different approaches to prevention have been debated widely, particularly in light of the US policy for its overseas programmes that favours abstinence based programmes over approaches that promote condoms. The ABC approach has been criticised by some as being too simplistic, and for failing to take into account the gender inequalities that exist in most countries of the world. For example, women who are faithful to their husbands can be infected if their husbands have unprotected sex with others; condoms are difficult to negotiate for women. Best practice in **prevention education** states that programmes should be comprehensive, high quality and evidence based, and should include accurate information on safer sex (including correct and consistent condom use), as well as abstinence, delay in onset of sexual activity, mutual fidelity, reduction of the number of sexual partners, and early and effective treatment for sexually transmitted infections.

There is increased support for **life skills education in schools** because of the recognised limitations of information-focused approaches to HIV prevention education. The life skills approach uses interactive methods to transmit knowledge on HIV as well as to shape attitudes and develop certain skills (decision-making, assertiveness, etc.) that enhances young people’s ability to make healthier choices, resist negative peer pressure, and avoid risky behaviour. To be effective, it is important to reach young people with life skills education before they become sexually active. There are sometimes difficulties in implementing life skills approaches in schools, because of the challenges of introducing participatory methods into a setting where most teaching is didactic. A limitation of the life skills approach is that it assumes that young people have the power and resources they need to make healthy decisions, which may not be the case for many young people.

As HIV is sexually transmitted, **prevention and management of sexually transmitted infections (STIs)** is an important prevention strategy. STIs increase susceptibility to HIV infection so using condoms to prevent STIs, and symptom recognition for early treatment are recommended strategies. High quality, non-judgemental STI care is essential, and the syndromic approach (enabling health workers to treat easily identified clusters of symptoms) endorsed by WHO and UNAIDS is generally used. This method achieves high rates of cure without the cost and delay of laboratory tests to identify specific STIs.

HIV Voluntary Counselling and Testing (VCT) is a prevention strategy as well as a gateway to care and support for those that test positive. Campaigns to ‘know your status’ have increased the uptake of HIV testing in many countries. A policy shift from VCT to routine counselling and testing has occurred in many countries. Routine testing involves proactively offering HIV tests to all clients in clinical settings with particular risks or conditions (such as tuberculosis (TB), STIs, pregnancy) with the client able to ‘opt out’ of testing. Routine testing also responds to the need to test children who have clinical conditions or risk factors that indicate possible HIV infection, and are unable to give informed consent.

Without interventions to prevent mother to child transmission of HIV, about one-third of infants born to HIV positive mothers will contract HIV through pregnancy, childbirth or breastfeeding. The entry point for prevention interventions is VCT (or routine testing) to identify HIV-positive pregnant women. Good outcomes in the **prevention of mother to child transmission (PMTCT)** can be achieved if an anti-retroviral drug, nevirapine, is administered to the mother at the onset of labour and to the infant within 72 hours of the birth. Although low-cost and effective, coverage of this

intervention remains disappointingly low in developing countries. Avoiding breastfeeding is an effective way to prevent transmission from mother to baby, but depends on the mother's ability to buy infant formula, have a clean source of water, and resist the cultural pressures to breastfeed. Exclusive breastfeeding for 6 months is lower risk than mixed breast and bottle-feeding, and is recommended if replacement feeding is not acceptable, feasible, affordable, sustainable and/or safe. Delivery by Caesarean section reduces the risk of transmission but is not a common strategy in most developing countries because of access, cost and safety.

Management and prevention of opportunistic infections and HIV-related illnesses can delay progression to AIDS. Given weak public health systems in many parts of the developing world, receiving good quality care and drugs to treat infections is highly variable. In many countries, NGOs and faith-based organisations (FBOs) provide a substantial percentage of health services, including mobile outreach to improve access to health care. Regular outreach services by qualified staff able to provide medications to keep opportunistic infections in check have helped people with HIV to manage their health and delay the need for ARV treatment.

Palliative care means care for the needs of people with life-threatening or life-limiting illnesses such as HIV, AIDS or cancer. Palliative care includes control of pain and other symptoms. It can also include supportive care such as counselling, psychological and spiritual support, home based care, treatment of illnesses or infections, and practical support for basic needs (food, water, shelter) and family support such as school fees, or legal help.

Home-based care (HBC) is the care and support of people with HIV or AIDS in their own homes to help them live healthier and positive lives. HBC reduces pressure on overburdened health systems as it extends care from the clinic to the home through trained health workers or volunteers. In many countries, HBC programmes have been instrumental in breaking down the stigma and discrimination associated with HIV. Most HBC programmes rely on volunteers to help family members to provide good care, promote adherence to ARV medicines where relevant, and refer families affected by HIV to other service providers for additional support. Volunteer caregivers should receive training (using an approved national curriculum on HBC if available) and regular supervision. Some programmes provide an allowance to maintain motivation of volunteers, while others have had good success using non-monetary incentives and careful selection criteria to retain volunteers.

Disease management with therapeutic ARVs has enabled many HIV positive people to regain their health. ARVs work by reducing the viral load in the blood, slowing down immune damage. Drugs are available free of charge in many developing countries through programmes such as the Global Fund to Fight AIDS, TB and Malaria but there are still costs to the client for laboratory tests and transport to health facilities for monitoring. Adherence is a concern: ARVs need to be taken for life, and defaulting can result in treatment failure or resistance requiring a switch to second or third-line medications which are costly and not always widely available. ARVs require adequate nutrition, another factor in adherence. CSOs play a role in supporting both access to and adherence of ARVs, by providing referrals, transport or laboratory costs, follow-up and adherence counselling. Some CSOs that have the technical and infrastructure capacity have been financed to directly provide ARVs to their clients as part of national treatment rollout plans.

Many CSOs provide **economic support for basic needs** (food, shelter, clothing, bedding, school support for children, etc.) to families affected by HIV. For households with limited income, coping with HIV – such as buying medication, transport to health care, and loss of income or job due to illness – can quickly exhaust family assets. Children may have to drop out of school because families cannot afford costs for uniforms, books, and additional fees. Older people may struggle to look after their children and grandchildren, and may have ailing health themselves. While it is recognised that material support is needed in the short term, sustainability of such inputs needs to be considered. Many programmes now aim to integrate support for basic needs with family livelihood strategies to improve household income in the longer term, and/or improved access to treatment and care to help breadwinners regain health to enable them to return to productive work.

Care and support for orphans and other vulnerable children involves a potentially large range of components. Educational support for children to attend or stay in school has already been noted as a basic need. Pre-school and playgroups for very young children in HIV affected households can reduce the burden of care for parents who are very ill or for households headed by orphans or older people. Children may need skills and resources to look after adults in the home who have become ill. Addressing the psychological needs of children affected by HIV is an area that is generally seen to be lagging behind others in responding programmatically. Institutional care of children is not promoted, as this separates them from families and communities and can delay healthy childhood development. Institutional care is also resource intensive; resources to support a single child in an institution can support larger numbers of children in well-planned community initiatives.

Once people infected and affected by HIV regain stability through care and support interventions, they often seek to regain their economic independence. Amongst other outcomes, **income-generating activities (IGAs)** can help restore dignity, decrease stigma, and improve nutrition of HIV affected families. Key approaches are grants or loans to establish IGAs. Many organisations support IGAs that focus directly on food production. Livestock ‘pass on’ schemes – where a household may be given livestock and the offspring is passed on to another household in need – have shown moderate success for some households. While recognising that grants may be needed for the most vulnerable, loan schemes generally demonstrate better long-term outcomes. Loans given to small groups create social support and motivation to individuals to succeed in their businesses. IGAs should be accompanied by training in managing small businesses.

People affected by HIV may need **legal support** to address a range of abuses: examples include discrimination based on HIV status, violence, or loss of land or property. While many programmes address legal issues on a case basis, it is acknowledged that more work is needed at community and national levels to develop policy (or enforce it when it already exists) to protect the rights of people infected and affected by HIV.

Gender plays an integral role in determining an individual’s vulnerability to HIV, ability to access care, support or treatment, and the ability to cope with HIV. There are a variety of ways to address gender in HIV interventions; the most evolved are ones that reduce gender inequalities and empower women and girls. These include strategies to improve the status of women, reduce violence against women, address inheritance rights, and ensure equal access to employment. Including both women and men in responses to HIV is also essential in challenging gender norms that heighten the risk of HIV.

The stigma of living with HIV still brings feelings of fear and shame. Stigmatising beliefs and attitudes lead to discrimination, which in turn creates barriers to accessing HIV prevention, treatment, care and support. On a personal level, stigma can mean isolation, abandonment, or violence. Challenges to **reducing stigma** include the need to address stigmatising attitudes of health workers, self-stigma of people with HIV, and long-held societal beliefs about the disease held by individuals, communities and institutions. People living with HIV are the best source for understanding stigma and its effects, and for appropriate ways to overcome it.

The **Greater Involvement of People Living with HIV and AIDS (GIPA)** is a principle that recognises the rights and responsibilities of people living with HIV to participate in decisions that affect their lives. The concept was formalised in 1994 and endorsed by 189 UN member countries in 2001. GIPA is recognised as the basis of many successful interventions worldwide. The benefits of applying GIPA are wide ranging. For individuals, involvement can improve morale and self-esteem, decrease social isolation, and improve health through better access to information about care and prevention. At community level, involvement of people with HIV can break down fear and prejudice and help overcome stigma and discrimination. Within programmes, the knowledge and experience that people living with HIV provide can result in more effective and sensitive services. For some, **MIPA (Meaningful Involvement of People Living with HIV and AIDS)** is a preferred term, which highlights a more active role of people with HIV as agents of change.

HIV has undermined years of development gains. Development organisations recognise that programmes in all sectors need to understand and respond to the ways in which HIV affects their work. **HIV mainstreaming** is described as adapting development programmes in all sectors to take into account beneficiaries’ susceptibility to HIV and their vulnerability to the impact of HIV and AIDS.

Finally, a number of **good practice principles in HIV programming** guide a wide range of development organisations and donors.

- Work collaboratively with government and other civil society organisations as part of a multi-sectoral response to HIV and AIDS
- Apply the GIPA principle
- Address gender inequalities
- Use participatory processes that genuinely involve target groups in all stages of the work
- Ensure equity of access to prevention, treatment, care and support services
- Monitor and evaluate to improve the work, document changes or outcomes, and disseminate learning to relevant stakeholders