
Supporting community action on AIDS in developing countries

Human resources for health exist in communities

This paper responds to some central assertions in the paper *Country Action Alliances to drive the HRH agenda* (circulated as background reading for the Oslo consultation on Human Resources for Health, 24-25 February 2005), which describes the diverse nature of partnerships required to enhance global and country level commitments to expanding human resources for health.

In response, this paper describes three examples of human resource development in community-driven HIV/AIDS programmes. The basic proposition is that acknowledgement, inclusion of and support for community based health initiatives is necessary to understand fully where health action is occurring and where potential for expansion lies.

This paper calls for an expanded definition of health systems that includes, values and resources the work being carried out by communities who are the frontline in responding to the HIV/AIDS epidemic.

Health care workers live in communities, and communities are providing health care: there is overlap between the two sectors and HIV care, including ARV treatment needs to exist both in communities and for health care workers.

The International HIV/AIDS Alliance's community-driven HIV/AIDS programmes

The International HIV/AIDS Alliance ('the Alliance') is an international non-government organisation which supports community action on AIDS in over 20 developing countries. The Alliance provides financial and technical support to community organisations which are fighting AIDS – organisations running HIV prevention programmes, organisations caring for orphans, vulnerable children and people with AIDS, and organisations providing AIDS treatment and care programmes.

The community based organisations supported by the Alliance have long standing roles and relationships in their communities. Sometimes these organisations have mobilised specifically around AIDS, but often they existed for other purposes in communities, and are adapting rapidly to work on AIDS as their communities are increasingly devastated by HIV/AIDS.

This paper briefly describes three of these programmes – in Zambia, Burkina Faso and Ukraine – which are providing ARV treatment. Each is a unique model of comprehensive community-led ARV treatment services, and relates to the formal public health system in different ways. The nature of this relationship is a critical part of the Alliance's work. We are striving to ensure that our programmes *support* public health systems and extend their services, rather than compete with them, or drain human or other resources from them. A key focus for the Alliance is strengthening the *interface* between public health systems and communities. This interface and the partnerships it necessitates require much greater attention and resources from donors and policy makers. We are working to build an expanded definition of health systems that recognises the substantial role communities play in providing health services, and acknowledges that communities need resources, support and inclusion in decision making in order to continue to play that role effectively.

Alliances to drive the human resources for health agenda

The Alliance supports much of the analysis in *Country Action Alliances to drive the HRH agenda*, in particular the comments about the need for human resource development to extend beyond the public sector.

Our experience in community level HIV/AIDS programming brings us into this dialogue. Our programmes are actively responding to both the crisis brought about by AIDS and its impact on the crisis in human resources for health. Communities are not waiting for global or national leadership, but are finding energy and capacity at a grass roots level, and are responding – setting up treatment programmes, caring for orphaned children, leading local HIV prevention programmes, advocating for equity and access. But this initiative and this capacity needs strengthening, both by building and enhancing the links to the public health sector, and by ensuring greater sustainability in financial and technical support for community based programmes.

Community engagement with ARV treatment in Zambia

The Zambian Government committed to scaling up access to ARV therapy in 2002. Their ARV programme aims to treat 100,000 people with ARV therapy by the end of 2005 through the public health system.

The Alliance started working with the Zambian Ministry of Health as their ARV programme planning began. We had experience of working with community based organisations providing home care and running community HIV prevention initiatives. Involvement in this work – care for the sick and dying, and working with communities on HIV prevention – taught us a great deal about the urgent need for ARV therapy and how much work is necessary in communities to make ARV therapy a safe and effective reality. We established a partnership

between the Zambian Ministry of Health, the Zambian Network of People with HIV/AIDS, the community based home care organisations and a traditional healers association to plan for the scale up of ARV therapy. We began this partnership with the shared acknowledgement that planning ARV programmes needed to take into account the major concerns of the people who need treatment.

These concerns include:

- a lack of money and food
- transport problems making access to clinics difficult
- lack of information about ARV therapy and much misinformation about ARV therapy
- concerns about equity – who gets access first?
- adherence issues and
- concerns about side effects, disclosure, reproductive health, prevention, stigma and discrimination.

After joint planning and training, the community engagement¹ work to support the Zambian government's ARV programme is now up and running in two sites, funded by the EU, USAID and the 'Saving Lives 1 by 1' programme of Aidsfonds, a Dutch NGO. HIV positive people are now working as patient advocates and treatment supporters, based in the government ARV clinics. HIV positive people are also working in community settings, at market places and other community centres, providing information and advice on ARV therapy and prevention. Home care workers are providing information about ARV therapy and prevention in homes and traditional healers are working with people with HIV to advise them about ARV therapy and with people on treatment to how best to manage side effects. Adherence support services are being provided to families and individuals, and HIV prevention interventions are an intrinsic to the treatment services.

This programme is being evaluated to monitor the difference it makes to treatment efficacy. The partnership with the Ministry of Health is a strong and supportive one and the Ministry explicitly acknowledges the value that community based work brings to the government treatment programme. Its success has led to a scaling up of the treatment support worker model to many of the under-served districts across Zambia.

Community provision of ARV treatment, Projet Orange, Burkina Faso

Projet Orange was established by Association African Solidarite, an Alliance partner. It is a community based care and support centre run by HIV positive people. It is providing ARV therapy and other health services and is staffed by doctors, nurses, community health workers and educators, many of whom are HIV positive. Projet Orange caters to the needs of adults and children. It is funded by the EU, USAID and the Friends for Life programme of Aidsfonds, a Dutch NGO.

Projet Orange was established to address the very poor access to ARV therapy in Burkina Faso. This situation of very poor access and very weak health infrastructure continues, with only very slow improvements.

While the public health provision of ARV therapy remains low, opportunities to work with government to strengthen their plans and develop technical skill are limited. But this picture is changing. Projet Orange staff have recently negotiated a deal with the Brazilian Ministry of Health for clinical training and supply of free ARV medicines for their clinic. The Burkinabe government is also participating in this novel partnership. Most recently negotiations were expanded to broker a more functional relationship between the Brazilian government and the Burkina Faso government in which training for health care workers and public health managers in the Burkina public health system will be provided. The Projet Orange staff and

¹ Please see more details of relevant Alliance publications at <http://www.aidsalliance.org/sw7418.asp>
ACER Project interim progress report - <http://www.aidsalliance.org/sw23263.asp>
What is community engagement for ARV treatment - <http://www.aidsalliance.org/sw7427.asp>

beneficiaries continue to build specialist HIV treatment and care knowledge and skill that can be drawn upon as plans for the government programme develop.

Scaling up ARV treatment in Ukraine

In 2004, the Alliance was appointed temporary Principal Recipient for the Global Fund in Ukraine; one of the key components of this programme is to scale up access to ARV therapy. The Alliance country office in Ukraine has experience in working with people with HIV, drug users, sex workers and others vulnerable to HIV. The focus of this work has traditionally been HIV prevention and community based care and support. But the Global Fund grant provided an opportunity to extend this knowledge and experience to include ARV treatment, in partnership with the Ukraine Ministry of Health and local community based organisations.

Alliance Ukraine staff, supported by technical specialists from the Alliance secretariat, have been trained in and are now managing drug procurement and supply, targeted treatment education and adherence support. In addition, Alliance staff are managing the training, mentoring and clinical monitoring of staff in the six public sector clinics that are the focus of this grant, in six of the most HIV affected regions in Ukraine.

This is a variation of the two previous models: ARV treatment is being provided by staff in the public health setting, but their HIV specialist training and mentoring is being provided by an NGO. Other local NGOs provide the supportive services – education, support, advocacy, HIV prevention services and outreach services. Importantly, these services are run by HIV positive people, drug users, sex workers and other community members. With over 1000 people, both adults and children, are now accessing ARV treatment, site assessments have been carried out to scale up to an additional nine regions within Ukraine.

These three case studies highlight just some of the roles that community organisations are playing in the provision of ARV therapy. In addition to more formal roles like community based health care workers providing clinical services, people with HIV are acting as educators, advocates, local experts, brokers, clinical mentors, drug procurement experts and adherence supporters. This work requires technical skill, and this technical skill needs resources for expansion. Public health systems will struggle to replicate the same levels of energy, entrepreneurial drive and local accountability that shape so many of these initiatives. Attention to resourcing health care in community based organisations, to building technical skill in community settings and to valuing and extending partnerships between community organisations and public health systems will be an essential requirement in global plans to expand access to ARV therapy in resource-limited settings. Communities are critically important to our conceptualising of health systems and must be acknowledged, supported and resourced accordingly. This applies most dramatically in the case of our commitments to scaling up access to ARV therapy.

For further information contact Susie McLean, Senior Policy Advisor - Care & Impact Mitigation, International HIV/AIDS Alliance, smclean@aid alliance.org or Dr Mandeep Dhaliwal, Head: Care & Impact Mitigation team, International HIV/AIDS Alliance, mdhaliwal@aid alliance.org