Keeping Commitments for HIV and AIDS: Access for All to Prevention, Treatment, Care and Support

A Position Paper from the Catholic HIV and AIDS Network (CHAN)

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The Asks

1. Maintain **long-term funding commitments** for continuation of current ART programming, start-up of new programming where needed and for the infrastructure to meet the Universal Access targets.
2. Provide **comprehensive and integrated prevention, treatment, care and support** for adults and children living with or vulnerable to HIV infection; build, strengthen and **sustain human resource capacity** to carry out comprehensive programmes through training and retention of skilled staff and volunteers.
3. Improve **support for infected and affected children** through increased and sustained access to paediatric diagnostics (testing) and child friendly treatment for HIV and HIV/TB co-infection; prevention of vertical transmission; and continued support for orphans and vulnerable children.

Background

The United Nations General Assembly Special Session (UNGASS) on HIV and AIDS in 2001 was a landmark event in the global response to HIV. *The 2001 Declaration of Commitment on HIV/AIDS* and subsequent *2006 Political Declaration on HIV/AIDS* adopted by the UN General Assembly provide both a global framework for the response to the pandemic and a promise by governments to deliver on these commitments.

The global community, through mechanisms such as the Global Fund, PEPFAR, and UNITAID, has collectively contributed more than US $32 billion to the response since 2002. Significant advancements have been achieved as a result of this investment – new HIV infections have decreased by 17 percent since 2001 and 5 million people living with HIV have been put on treatment – a 10-fold increase since 2003.[1]

Despite these advancements, funding for HIV has seen a sharp decline in the recent past. In anticipation of the MDG Summit in October 2010, UN Secretary-General Ban Ki Moon noted that between 2011 and 2015 an estimated US $28 billion to US $50 billion yearly would be required to reach universal access targets.[2] At the 2010 Global Fund Replenishment conference, pledges fell far short of the US $20 billion requested to continue and expand the Fund's programmes in 145 countries over the next three years. Since then some donor countries have either scaled back or withdrawn their pledges to HIV and AIDS entirely.

Flat-lining budgets and funding cuts effectively rescind the commitments made at UNGASS in 2001 and 2006, lead to backtracking of progress made, and translate into millions of unnecessary deaths. It is estimated that proposed financial year 2012 cuts by the United States government[3] could result in 448,866 people being eliminated from anti-retroviral treatment; 299,294 orphans and vulnerable children losing their food, education and livelihood assistance; and 20,000 babies born with HIV each year.[4]

The Catholic HIV and AIDS Network (CHAN) is a network of Catholic Church-related partnership organizations from Europe, North America and Oceania that support HIV programmes throughout the world.

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1 *General Assembly Holds Review of International Efforts against HIV/AIDS: Told Progress Made, But Epidemic Continues to Outpace Global Response.* United Nations General Assembly. June 9, 2010 Press Release. Available at http://www.un.org/News/Press/docs/2010/ga10946.doc.htm

2 *New Funding Needed to Fight HIV/AIDS, TB and Malaria, UN ChiefWarns.* September 21, 2010. Available at http://interdiscussion.blogspot.com/2010_09_21_archive.html

3 House Resolution 1, passed by the United States House of Representatives, would reduce global health funding by more than US $1 billion from 2010 levels.

4 The Foundation for AIDS Research (amFAR). *Devastating Impact Projected from Global Health Funding Cuts in House Continuing Resolution.* 25 February 2011. Available at http://www.amfar.org/hill/article.aspx?id=9525.

Global statistics on HIV and AIDS clearly show the need for an intensive response to treating people living with HIV worldwide. According to WHO Guidelines, of the 33 million people living with HIV, 14 million are immuno-compromised enough to need drugs now.[5] Although the 5 million now on treatment represent a remarkable achievement, a 65 percent treatment gap still exists, showing the need for a scale-up of treatment. Further, there is a need for a sustained and comprehensive response to HIV and AIDS beyond anti-retroviral treatment. A recent study by the Ecumenical Advocacy Alliance[6] demonstrated that most faith-based organisations have been experiencing funding shifts since the end of 2009. The impact ranges from patients being forced off treatment, to agencies being unable to enrol new patients in treatment programmes, to staff layoffs and reduced programme outreach. Additional 2011 research conducted by the Catholic HIV and AIDS Network (CHAN) specifically among Catholic organisations, which forms the basis of this paper, points to similar results – consistent long-term funding and commitment from donors is needed in order to maximise the effectiveness and reach of services for adults and children.

The Catholic Response to HIV and AIDS

Catholic organisations have been involved in a comprehensive HIV and AIDS response since the early 1980s, and currently have active programmes in at least 114 countries. For example, ten of the largest organisations within the Catholic HIV and AIDS Network (CHAN) collectively spent US $241,244,145 on HIV and AIDS in 2010 worldwide.[7] These international Catholic partnership organisations provide both funding and technical assistance to community-based and Catholic organisations responding to HIV and AIDS in low-and middle-income countries. During the research CHAN selected 11 organisations working at community level to underline the situation facing organisations working in the community. These 11 organisations have a combined annual budget for HIV and AIDS of over US $46 million annually at the country level. While they represent just a fraction of the overall Catholic response, these 11 organisations alone serve – on an annual basis – over 90,000 clients on ART, 25,500 pregnant women through PMTCT, 120,000 HIV-positive clients in home-based and palliative care, 314,000 clients in voluntary counselling and testing, 52,000 orphans and vulnerable children, and 5.5 million people through prevention initiatives. Catholic organisations have had a long-term presence in most countries where they work, are engaged in comprehensive care and support, and are deeply rooted in the communities they serve – thereby making them an integral part of the global HIV and AIDS response.

Maintain Long-Term Funding Commitments

"Universal access means more than ensuring that those who need treatment or prevention services receive them. It implies an extra effort to reach those who are marginalized, criminalized or disenfranchised." Ban Ki Moon[8]

Universal access is a broadly defined term. While not necessarily meaning 100 percent coverage of all HIV related services, it may be defined as the commitment to move to an increased level of access for the most effective interventions that are "equitable, accessible, affordable, comprehensive and sustainable over the long-term." With the 2010 Universal Access goal in mind, ninety-nine countries set their own targets with most countries aiming for 80 percent treatment coverage.[9] World Health Organization and United Nations targets for scale-up to achieve universal access have not remained

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5 World Health Organization. 2008. *Essential Prevention and Care Interventions for Adults and Adolescents Living with HIV in Resource-Limited Settings.*

6 Ecumenical Advocacy Alliance 2010. *Assessing the Impact of the Flat-Lining of Treatment Funding on HIV-Related Services Delivered by Faith-Based Organizations.*

7 Report by CHAN members to Caritas Internationalis.

8 *Noting Progress to Date, Ban Urges Greater Efforts Against HIV/AIDS.* 9 June 2010. Available at http://www.un.org/apps/news/story.asp?NewsID=34977&Cr=aids&Cr1

9 UNAIDS (2009) "What Countries Need: Investments Needed for 2010 Targets"

constant. After the 2001 UNGASS, the ambitious "3 by 5 goal" of putting 3 million people on ART by 2005 was set. Although this goal was not achieved until 2007, in 2006 these same international bodies established the commitment to universal access to HIV treatment, prevention, care and support by 2010. While universal access targets had only been met in eight countries by the 2010 deadline, a total of 5 million people had been put on treatment by that time. With 14 million people living with HIV worldwide meeting WHO guidelines for treatment eligibility, this has resulted in a treatment gap of 65 percent. Clearly universal access targets have not been met.

In Uganda, People Die While Queuing for Access to ART[10]

Nsambya Home Care Programme is a Catholic community-based organization in Kampala, Uganda providing home-based and palliative care to 11,000 clients, ART to 5,000 clients (including 300 children), voluntary counselling and testing, HIV prevention, and care and support to orphans and vulnerable children. Since 2007, the organisation has experienced a cut in nearly 75% of its total funding. Trained staff have been laid off, and medication and supply inventory – once responsive to burgeoning demand – is now held to a bare minimum. Funding from international donors, such as PEPFAR, has been flat-lined. As a result, in the past year Nsambya has been unable to enrol new clients on ART unless people already on treatment pass away, nor are they able scale up services to meet the demands of people in need of treatment but not already enrolled in ART programmes. Nsambya's coordinator reports that people are dying in the process of waiting to be enrolled in ART. According to Nsambya's coordinator, failure to put people on treatment results in "missed opportunities and early mortality."

All organisations interviewed for the 2011 CHAN research have experienced some degree of funding flat-lining or budget cuts. While smaller local organisations tend to steer away from major donors most receive funding from these entities through their larger partners (e.g. Catholic Relief Services, CAFOD, Cordaid, and Trócaire), and thus are negatively impacted when these funds are cut. In most situations, organisations have been instructed not to enrol new clients in treatment despite the growing need and clinical eligibility.

As reported by a CHAN member, within the Global Fund model, frequently if one sub-recipient mismanages funds the entire country suffers by having the whole of their grant suspended. While accountability is important, fiscally responsible organisations should not be made to suffer for the wrong-doings of others. All governments should maintain their funding commitments to ensure continuity of services for HIV intervention programmes that have proven to be transparent, accountable, efficient and effective.

The need for uninterrupted and dependable sources of funding is critical for an effective HIV and AIDS response. The major recurring theme of the 2011 CHAN research is 'uncertainty.' Many respondent organisations have no guarantee of funding beyond the current fiscal year, and equally worrying, many have experienced significant delays in promised funding. This uncertainty makes the implementation of services extremely difficult, while simultaneously, donors demand greater efficiency.

[10] From interview with Coordinator, Nsambya Home Care Programme Uganda (Kampala), 9 March 2011.

Provide comprehensive prevention, treatment, care and support

"I keep hearing I need to do more with less; this is just not possible."[11]

The 2010 research by the Ecumenical Advocacy Alliance (EAA)[12] pointed to the need for funding of wider care and support initiatives that are essential to an effective overall response to HIV; these have been neglected in recent years and will be further compromised by the latest funding crisis. According to the EAA research findings, many agencies had previously scaled up in response to donor requests to reach targets and, when funds were either cut or flat lined, were then unable to sustain these services. The initial EAA research pointed to the need for consistent long-term funding and commitment from donors in order to maximise the effectiveness and reach of services, a focus on health systems strengthening and nutritional support as a part of a comprehensive HIV response; these findings were re-affirmed by the 2011 CHAN research.

While challenges with regard to people being forced off treatment entirely were not reported in the 2011 CHAN research, there have, however, been issues with regard to lack of adherence because of drug shortages, people unable to travel to clinics to access ART because they are unable to pay for transportation and lack of nutritional support. Testimony from the 2011 CHAN research indicates that funding for wider care and support services is also declining. Such support services include psychosocial support, support for orphans and vulnerable children, nutrition, skills training for returning to work/livelihoods, and income-generating activities. These support services are essential to a comprehensive HIV and AIDS response. Funding cuts are likewise affecting HIV prevention efforts.

"If they [PEPFAR] cut funding, no one else is going to fund us. We're too big." – Board Chairperson, Eastern Deanery AIDS Relief Programme on uncertainty his organisation currently faces regarding the possibility of funding cuts.

Currently, this programme in Kenya provides ART to 12,000 clients (including 1,500 children, and comprehensive care and support to 19,000 clients. Their integrated model of care includes home-based and palliative care, HIV prevention, and psychosocial support.

Comprehensive care and support improves drug adherence, which can help to delay drug resistance and supports the overall effectiveness of HIV and AIDS treatment, thereby saving money in the long-term on more costly second- and third-line treatment regimens. For instance, the cost of first line treatment is US $151 per year, but a supply of third line treatment is US $2,291.[13] At the same time, evidence shows that treatment is one of the most effective forms of prevention and has also been successful in the reduction of orphan-hood.

Wider care and support remains equally as critical as ART, but has unfortunately not received the attention its inclusion in the universal access targets promised. Despite being the third pillar of Universal Access, care and support is scarcely accounted for in formal, funded national AIDS responses or policy-making. At the global level, HIV care and support is not listed as a priority for many international institutions and donors. Therefore the work of community and family caregivers and home-based care organisations has remained largely invisible and inadequately supported.

Numerous studies have shown that faith-based organisations (FBOs) are critical providers of health care, especially in rural areas where innovative models of home – and community-based care, largely dependent on faith-linked networks, have been established in many parts of the developing world.

Mapping research by the African Religious Health Assets Programme in 2008[14] revealed that the contribution of FBOs in terms of health facilities at the country level in Africa is as high as 30 percent in both Uganda and Zambia, with an emphasis on hard-to-reach rural health facilities. In fact, FBOs provide up to 70 percent of the health care available in rural Zambia.[15] Marginalised rural populations could be forced to bear the brunt of funding cuts.

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[11] From interview with program coordinator in Namibia.

[12] *Assessing the Impact of the Flat-Lining for Treatment Funding on HIV-Related Services Delivered by Faith-Based Organizations."* Ecumenical Advocacy Alliance. 2010.

[13] UNITAID 2010. *Better Access to Testing and Treatment for HIV-Positive Children: The Medicines Patent Pool Initiative.* PowerPoint Presentation Delivered on 16 June 2010.

[14] Schmid B, Thomas E, Olivier J, and Cochrane JR. 2008. *The contribution of religious entities to health in sub-Saharan Africa.* Study funded by Bill & Melinda Gates Foundation. Unpublished report. Cape Town: African Religious Health Assets Programme.

[15] African Religious Health Assets Programme (ARHAP). 2006. *Appreciating Assets: The Contribution of Religion to Universal Access in Africa.* Report for the World Health Organization. Cape Town: African Religious Health Assets Programme.

Human resource capacity to carry out effective HIV and AIDS prevention, treatment, care and support remains a major challenge, and over half of those interviewed during the 2011 CHAN research had experienced cutbacks in staff and/or volunteers as a result of the funding crisis. This has occurred in already impoverished countries with high unemployment rates. Poverty is still a major obstacle in addressing HIV treatment, care and support.

Cuts in funding for HIV hamper progress in southern Africa

In Namibia, Catholic AIDS Action has been told by major donors that they need to keep the same targets for comprehensive care and support despite a 20 percent budget cut. In efforts to maintain consistent numbers of clients enrolled in home-based care, accessing voluntary counselling and testing services, receiving support as orphans and vulnerable children, and gaining knowledge through comprehensive prevention messages, Catholic AIDS Action is facing possible staff layoffs, the inability to replace aging vehicles, and severe cuts to incentives for volunteers already living in poverty. This is occurring in a country where the unemployment rate is already 51 percent.[16]

Due to funding cuts, St. Mary's Outreach Centre in Kwa Zulu Natal, South Africa was temporarily closed in December 2010, resulting in the inability to access care for 900 home-based care clients and 2,500 orphans and vulnerable children. To resolve the funding shortfall, St. Mary's cut staff from 23 to 14 and cut volunteers from 382 to 320. Most volunteers are women, and are directly impacted by cuts and reduction in incentives that used to alleviate their own poverty. This also includes the provision of nutritional support in the form of food parcels and the implementation of community food gardens; many of the volunteers who had previously received this support are themselves living with HIV. Nearby clinics are also understaffed, and must close when they reach their quota for the day; this results in people being turned away.[17]

Meanwhile, funding for training is diminishing, and community-based organisations are finding it increasingly difficult to secure funding and approval for training and capacity building of staff and volunteers. Moreover, funding shortfalls are likely to make some of the Millennium Development Goals, including halting and beginning to reverse the spread of HIV and AIDS (MDG #6) and halving the number of people living in extreme poverty (MDG #1), unachievable by 2015.

Support for infected and affected children

While access to HIV–related services for children has improved in recent years, there is still a lack of access to early diagnosis and treatment for many children living with HIV or with HIV/TB co-infection. Additionally, continuing obstacles to uptake of PMTCT still exist, and virtual elimination of vertical HIV transmission will not be achieved without sustainable resources. In spite of the progress made, children are still less likely than adults to receive lifesaving treatment. While about 90 percent of the world's children living with HIV are in sub-Saharan Africa, only 26 percent of children in need in this region are receiving antiretroviral therapy; this lags behind the global average. Early identification and treatment of infants living with HIV is critical to their survival. At the end of 2009, UNAIDS estimated that 2.5 million children were living with HIV, among whom 1.2 million urgently needed ART, but only 356,000 were currently receiving such treatment. The availability of fixed dose combination treatments for children living with HIV or HIV/TB co-infections need to be accelerated to reduce side effects and promote adherence. The death rate among untreated HIV-positive children is very high: 50 percent of such children die before their second birthday. The mortality rate of untreated children living with HIV reaches 80 percent by five years of age.[18]

[15] African Religious Health Assets Programme (ARHAP). 2006. *Appreciating Assets: The Contribution of Religion to Universal Access in Africa.* Report for the World Health Organization. Cape Town: African Religious Health Assets Programme.

[16] From interview with Executive Director of Catholic AIDS Action Namibia. 10 March 2011.

[17] From interview with Coordinator, St. Mary's Outreach Centre. 14 March 2011.

[18] UNICEF, UNAIDS and WHO 2009. *Children and AIDS Fourth Stocktaking Report.*

The Need for Child-Friendly Treatment

According to Fr. John Toai of the Mai Tam Centre for HIV-positive mothers and children in Vietnam, children co-infected with both HIV and TB in his centre are forced to take 9-12 tablets per day. Often, these children are unable to eat after taking the medicines. The pills are hard to swallow and several side effects have been reported. Some of these children cannot gain access to paediatric doses, and, according to Fr. Toai, attempts to cut up pills meant for adult use often result in under or over-dosing. This shows the need for greater progress with developing combined medicines that could treat multiple infections and are easy to administer to infants and children.[19]

Vertical transmission of HIV is another grave concern. Ninety percent of HIV-positive infants are born to mothers who were never tested and never received prophylaxis to prevent mother to-child or vertical transmission. This situation continues to occur despite commitments by governments and the international community to ensure pregnant women and their infants have access to effective treatment. Indeed, only about 51 percent of pregnant women living with HV were screened for treatment eligibility in 2009. [20]

The need for improved access to paediatric formulations of antiretroviral drugs, prevention of vertical transmission, and care and support for orphans and vulnerable children is more urgent than ever. UNITAID will soon end its 5-year mandate as purchasing facility for paediatric AIDS drugs, which currently covers the purchase of approximately 50 percent of worldwide paediatric antiretroviral drugs (in partnership with the Clinton HIV/AIDS Initiative). The Global Fund and PEPFAR had initially indicated an intention to take up this role, but as previously indicated, these entities are currently experiencing funding cuts of their own. As UNITAID shifts procurement of paediatric formulations to individual governments in a governmental ownership model, there is a need for capacity building and health systems strengthening at the national and grassroots levels in low-and middle-income countries in order to meet the current and growing demand for services. Meanwhile, obstacles to accessing PMTCT and low levels of coverage still exist in many parts of the world.

Funding cuts and flat-lining also affect orphans and vulnerable children. A Ugandan study revealed that ART rollout has been associated with an 81 percent reduction in mortality of uninfected children and an estimated 93 percent reduction in orphan-hood.[21] Such progress is unsustainable if people die while queuing for treatment, thereby increasing the incidence of orphan-hood. In Vietnam, the Archdiocese of Ho Chi Minh City is struggling to provide support to school children and to nearly 400 orphans and vulnerable children. Funding cuts could result in an increased risk of HIV infection for these vulnerable children.[22]

Conclusions

With all of the progress that has been made since 2001, it is imperative that the United Nations member states do not backtrack on their commitments to HIV and AIDS treatment, prevention, care and support for both adults and children. Therefore, the Catholic HIV and AIDS Network calls on governments to:

1. Maintain **long-term funding commitments** for continuation of current ART programming, start-up of new programming where needed and for the infrastructure to meet the Universal Access targets.
2. Provide **comprehensive and integrated prevention, treatment, care and support** for adults and children living with or vulnerable to HIV infection; build, strengthen and **sustain human resource capacity** to carry out comprehensive programmes through training and retention of skilled staff and volunteers.
3. Improve **support for infected and affected children** through increased and sustained access to paediatric diagnostics (testing) and treatment adapted for use in poor settings, in particular fixed dose combinations for infants and children living with HIV/TB co-infection; prevention of vertical transmission; and continued support for orphans and vulnerable children.

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[19] Testimony from Fr. John Toai, Mai Tam Centre, to Caritas Internationalis. 2010.

[20] *UNAIDS Strategy Goals By 2015: Vertical Transmission and Maternal Mortality.* Available at http://www.unaids.org/en/strategygoalsby2015/verticaltransmissionandmaternalmortality/

[21] Mermin J, Were W, Ekwaru JP, Moore D, Downing R, Behumbiize P, Lulu JR, Coutinho A, Tappero J, Bunnell R. 2008. *Mortality in HIV-infected Ugandan adults receiving antiretroviral treatment and survival of their HIV-uninfected children: a prospective cohort study.* Lancet 371: 752 – 759.

[22] From interview with Director of Mai Tam Shelter, Committee of Pastoral Care for PLWA, Archdiocese of Ho Chi Minh City, Vietnam. 9 March 2011.