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HIV/AIDS - a threat to human dignity

Personal reflections by Calle Almedal

Calle Almedal was born in Sweden in 1945; after six years of reflection, he left the Lutheran Church to join the Catholic Church in 1969. He studied some theolog,y and has a degree in nursing and in public health. He worked for the Norwegian Red Cross, and is currently senior advisor to the Joint United Nations Programme on HIV/AIDS, based in Geneva. This article does not reflect an official UNAIDS position.

Twenty years into the worst pandemic mankind has ever experienced, that may change Africa more than slavery and colonialism did, we still try to understand some of the basic underlying issues.

The terms “human rights” and “rights-based approach” are used more and more frequently. But these are secular words. Perhaps it is better for Christians and people of other faiths to try to use their own language. Most religions have terms that cover “human rights” and go beyond this secular term. “Inherent human dignity” implies something more than “human rights”, since the latter come from humans and not from God. When we violate human rights, we violate something that we, as humans, have said we should not violate. This is serious enough. But when we violate “inherent human dignity”, the matter takes on another dimension. It is not only the person *per se* whom we violate, but also God. This happens all too often, in too many churches.

A “rights-based approach” refers basically to seeing HIV/AIDS in the light of the United Nations Declaration of Human Rights and of various other documents signed by UN member states, and to making sure that people with HIV/AIDS have the same rights as all other citizens of the country they live in. If this is not the case, "watchdog" organizations (and more churches should become such organizations) should hold governments responsible for these violations, or make sure that governments hold the violators responsible. It should, for example, be forbidden to expel people from houses and jobs because they happen to be HIV-positive, or to deny them access to work on the same grounds. Twenty years into the HIV/AIDS pandemic, a rights-based approach should also mean that all organizations have work-place policies that consider HIV+ employees and their rights in the work-place.

In a faith-based setting, the approach must transcend a secular one. The imperative is a divine one, and the stakes are higher for all involved. Further, religion can show the way for the secular world to follow.

If we believe that we have an inherent human dignity because we are created to be human beings by God, and if we believe that we have that human dignity irrespective of gender, ethnic belonging, social status, etc., then we need to make sure that we all enjoy this dignity fully. HIV/AIDS does not take human dignity away from those who happen to carry this particular virus. But man does. Man takes away the dignity of the pregnant woman who does not know that she is HIV+, because she has not been tested - because she is afraid of stigma/discrimination - and in any case, there is no medication available. Not only does man take away her dignity, but also the dignity of her unborn child.

Stigma and discrimination, and non-access to treatment are the two biggest obstacles we currently experience in the vast field of HIV/AIDS. They are also the most flagrant violations of human rights and of inherent human dignity. And yet churches, using religious language, perpetuate them. What more burning sign of stigma

can there be than refusing to allow HIV+ people to get married? How better can you express your contempt of HIV+ people working for churches than by not considering how they might gain access to treatment?

For the churches, a rights-based approach must mean transformation of the churches themselves, and a sharper focus on the divine origins of inherent human dignity. While a secular rights-based approach is, basically, more legalistic and rooted in laws, a religious one has its roots elsewhere.

For over two decades, church-related health care facilities have done a very good job in caring for people who have HIV-related diseases. They were in the forefront of the pandemic from the very start. The same health care facilities have also counselled people who are HIV+, and church organizations have taken care of widows, widowers and orphans. In this way, churches have assisted communities in hard-hit countries to strengthen their mechanisms for coping with the onslaught of HIV/AIDS. In this respect, churches have furthered a rights-based approach by making sure, through their health care facilities, that people with HIV/AIDS get care that is as appropriate as possible. Churches have also shown respect for HIV+ people's inherent human dignity by caring for them.

The discrimination against people with HIV/AIDS, and the lack of medication for HIV-related disease and of anti-retrovirals are perhaps the most flagrant violations against HIV+ people's rights and dignity. The lack of appropriate medication is, furthermore, a flagrant sign of the inequity in the world and of the global lack of solidarity - especially painful to witness in churches. The combination of stigma/discrimination and lack of medication is a lethal one, not only for the individual, but also for communities, countries… It is the reason people do not want to get tested. This leads to more infections in adults, and more babies born HIV+. As people do not know if they are HIV+ or not, they do not go for medication, even where it is available.

Churches, and especially their leaders, have an enormous responsibility here. If church leaders would become forceful advocates for access to treatment, as some have done in South Africa in innovative partnerships with activist groups, and if, at the same time, they would make sure - by sermons and church-wide programmes - that stigma is eradicated, then more people would be tested, there would be less transmission of HIV amongst adults, and less babies would be born with HIV. In essence, more lives would be saved. By following this path, church leaders would not only show proof of a rights-based approach, but they would also show respect for The One behind our inherent human dignity.

Following electronic discussion fora and reading what churches say that they do, or want to do, one gains a disturbing impression that there is still a heavy focus on the condom issue. In many cases, what is said and written is untrue, and there is a heavy focus on abstinence and monogamy. Laudable as that might be, it is not enough. Work in the field of HIV/AIDS is about three issues: prevention, care, and human rights/human dignity. And at the centre of the three are people living with HIV/AIDS. They are our brothers and sisters who, unfortunately, have contracted HIV.

There has to be a balance between prevention, care, and rights/dignity. As we have said, churches have being doing fine in care, and are now heavily involved in prevention, although is sometimes is difficult to understand the content of their programmes. But they are, as yet, far too little involved in the rights/dignity issues. As long as this situation prevails, we will have vain discussions on condoms, abstinence and monogamy that might lead people to believe that debate alone is a preventive or healing activity. It might also hinder churches leaders from taking an active part in advocacy for access to treatment and eradication of stigma.

So what can churches do in a rights-based approach that keeps inherent human dignity in focus? On prevention, they can establish programmes that assist young people to postpone their sexual debut - by totally ***re-thinking*** how they approached the issue ***before*** HIV came since, apparently, it was not too successful. They can establish clear objectives, indicators, monitoring and other mechanisms necessary for any activity to be successful. Such an approach would save thousands of lives in high-incidence countries.

In health care settings, they can make sure that good practices are kept up and enhanced, but

they can also attempt to increase access to medication, and become watchdogs to make sure that the necessary medicines reach the people who need them.

On rights/dignity issues, churches need to elaborate programmes for advocacy and stigma eradication. Here again, church leaders need to have clear objectives, indicators and monitoring mechanisms in order to make sure that what they want to achieve really happens. And they must reach out to people living with HIV/AIDS, not as the objects of charity, but as the precious ressources they have proven to be everywhere they have been accepted as equal partners.

ICASA 2003: Access to Care: Challenges

Dr. Sue Parry
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The 13th biennial "International Conference on HIV/AIDS and Sexually Transmitted Infections in Africa" (ICASA) was held from September 21-26, 2003 in Nairobi, Kenya. ICASA traditionally reviews and critically analyses any new responses to the pandemic as well as identifies priorities and effective strategies. Through diverse presentations and a community programme to complement the scientific programme, the conference aims to explore the many challenges presented by HIV/AIDS and the translation of clinical research findings into standards of care.

Around 8000 delegates braved unusually trying conditions to deliberate on this year's theme of: "Access to care: Challenges," which was most appropriate considering Africa is home to 70% of people living with HIV/AIDS worldwide. Here less than 10% of PLWA have access to palliative care and treatment of opportunistic infections, and less than 4% have access to any form of anti-retroviral therapy. In the developed world such treatment has turned HIV/AIDS into a chronic manageable illness.

Providing access to care remains a major challenge in Africa, where HIV/AIDS presents an enormous burden to families, communities and to health care systems. High drug cost is the most common limit on access to ARV. Health sector capacity, including infra-structure and shortage of trained personnel are also constraints. Few people know their sero-status due to a combination of denial, stigma, fear, lack of VCT services and a reluctance to find out their status because of the unavailability of aftercare.

The universal goal remains to meet the basic right for access to the whole continuum of comprehensive care from home based to palliative care, treatment of opportunistic infections and management of HIV disease.

Africa's long haul to a credible effort to mitigate the epidemic must include building human capacity, addressing gender inequalities and economic deprivation, protecting public services, fostering democratic governance and strengthening political commitment, mobilizing resources to fight the epidemic, protecting human rights and forging partnerships between stakeholders, especially people living with HIV/AIDS.

Perhaps the biggest challenge is to address the issue of stigma and discrimination and thus to create an enabling environment for open disclosure and mitigation.

Notably there was a higher profile than in previous conferences to issues pertaining to orphans and vulnerable children, Faith based organizations (FBOs), human rights, and the humanitarian crisis of Sub-Saharan Africa, which is compounded by the impact of HIV/AIDS.

There were a fair number of events with religious significance and various religious organizations manned information booths. Satellite sessions and workshops, as well as abstracts and posters, covered a wide range of subjects which included prevention, counseling, OVC, strategies for women of faith, capacity building, community mobilization, collaborative relations, stigma and discrimination.

Through all the presentations, in what ever format given, there emerged five major challenges:

1. Scale-Up

The need to drastically scale-up access to antiretroviral therapy was repeatedly and eloquently voiced. Prevention and treatment can no longer be separated from each other. Whilst there is no ethical justification for denying equal access to appropriate and life saving medications, it must also be recognized that ARVT is not the panacea for HIV/AIDS. The shift in focus in the direc

tion of this was both heartening because of need, and alarming because ARVT will not replace many key remaining problems:

- Prevention will remain a challenge.
- Orphans are already present in their millions, with millions more to come before ARV s can really effectively increase the parent-to-child relationship time.
- Palliative care will always be necessary, even in the era of ARVs, as there still remains no cure for this condition.
- The determinants that are driving the epidemic remain and will not be addressed by the arrival of ARVs.

The need to address all these criteria, and more, remains just as crucial as ever. With the focus on scaling up, the need for capacity building is urgent.

2. Women

Because of the increasing impact of the epidemic on women, (58% of those infected in SSA) there must be additional focus on women in the African response. To seriously address this, issues of justice and the voice of advocacy must not be muted. Gender and culture are talked about but insufficient action is forth coming.

3. Humanitarian Crisis

The current crisis in Sub-Saharan Africa has highlighted the impact of HIV/AIDS.
FBOs are already key respondents, using their infrastructure, knowledge, credibility and networks to assist agencies in dealing with the food crisis. The need to integrate HIV/AIDS mitigation into broader development and humanitarian initiatives is now essential.

4. HIV/AIDS is a Human Rights issue

Governments must be made accountable to their Constitutions and the Conventions to which they are signatory. This is a prerequisite to upholding the rights of PLWHA, before we enact any further laws and policies to deal with the problem.

5. Stigma and Discrimination

These are 'heart issues' and no amount of legislation alone will overcome this hurdle.
FBOs have a major role to play in this arena.

Why do FBOs need to be represented at these international conferences?

FBOs have been in the forefront of care and support initiatives since the onset of the epidemic. Home-based care grew out of a Church initiative. In many countries in Africa FBOs provide over 50% of education and health care. FBOs have the greatest consistent access and credibility with the population at large.

However FBOs seldom document or monitor and evaluate the strengths and impact of their programmes. It is difficult to measure their cumulative impact compared to the more visible project responses of developmental agencies. As a consequence, faith based HIV/AIDS activities remain under supported.

The current call is to 'Think big, Act big.' The UNAIDS focus at the conference was on building partnerships for accelerated access to care, to facilitate formulation of shared goals and priorities as well as to define the environment which will enable African countries to implement effective HIV/AIDS programmes. FBOs, however, tend not to readily network, even within their own denominations, and are cautious of collaboration and partnerships, especially with secular organizations. In light of the enormity of impact of HIV/AIDS, there is serious need to re-examine this situation.

With regard to the overwhelming needs of affected children, it has been demonstrated and documented (WCRP & UNICEF Study 2003) that FBOs have an irreplaceable capacity to meet the needs of children orphaned and made vulnerable by HIV/ AIDS in Africa. Families and local communities are the front-line caregivers and have demonstrated remarkable resilience and creativity in addressing the myriad needs of these children.

Despite all the increased commitments by political leaders there is yet to be seen an effective response continent wide. Many gaps remain. FBOs need to be seen both as credible and equal partners in the fight against HIV/AIDS. Their lead role in so many areas needs to be acknowledged, their experiences and activities heard, shared, built on, refined and scaled up. FBOs also need to avail themselves of current information and technology that is available so as to access resources from non-traditional sources, to share best practices and to collaborate and network more effectively.

Too many people have died already, too many

people are suffering dreadfully; suffering not only physical pain but also the pains of rejection, isolation, the fear of dying alone and the consuming anxiety 'who will care for my children?'

The Church has a powerful voice of advocacy, it is not only the fingertips of Christ to the people, it must be seen and heard in the international forums, bringing her experiences, her mandate, her prophetic voice as well as compassion and realism to the debate.

As Fr. Robert Igo OSB stated in his booklet: 'HIV/AIDS: the Missing Dimension: "Antiretroviral therapy may provide the *means* to live, but faith gives the *reason* to live."

Providing hope amidst despair - the example of BOCAIP

H. Ruth Thiessen

Vision, commitment and sacrifice are the qualities that come to mind when talking of the foundation of the Botswana Christian AIDS Intervention Programme (BOCAIP). This is a national organization based in the small southern African country which today has the highest HIV infection rate in the world: 38% for adults from 15-49 years of age. And in a country of only 1.6 million people there are over 80,000 orphans.

The vision of an HIV/AIDS intervention strategy uncompromisingly Christian in values and approach was shared by the churches, the community, the para-church organizations and the government of Botswana.

The government's involvement, which was backed by encouragement to adopt a multisectoral approach to curbing the spread of the pandemic, included a call to prayer by the then President K. Masire, who declared September as a month of prayer for HIV/AIDS. That was in 1996, the same year that BOCAIP was born.

The churches and the para-church organizations showed their commitment to the fight against HIV/AIDS by adopting an approach rooted in Christian principles and values. This earned them the respect of those they partnered in various capacities and at various levels.

Especially at the beginning when there were inadequate resources, sacrifice marked the foundation and establishment of the organization. For the first three years, there was little or no funding and the various centres relied on part-time volunteers because they could not afford to hire full-time staff. However, the work had to proceed, which meant services were delivered with minimal resources acquired from the churches in the locality.

It was on the basis of such dedication and sacrifice that BOCAIP earned the respect of donors. In 1999, the first major donor, Bristol Myers Squibb, through its "Secure the Future" foundation, made a commitment to support the work of BOCAIP for three years. This same foundation now funds some of the work in the field of orphan care undertaken by BOCAIP centres. Many other donors, including Norwegian Church Aid, SIDA, CIDA (in partnership with the Mennonite Central Committee), UNICEF, the government of Botswana, the Self-Help Fund of the US ambassador in Botswana, and others have made donations for specific projects. Funding negotiations are currently going on with a local government ministry. The ministry needs to approve all proposals and budgets through a new major donor, the Africa Comprehensive HIV/AIDS Partnership (ACHAP), and the Bill and Melinda Gates Foundation.

All the entities which came into partnership with BOCAIP bought into what the organization was already doing, supporting it by doing what they knew how to do best. This included mobilizing communities to respond to the pandemic by equipping them with the requisite knowledge and skills, and stimulating them to initiate community-based initiatives that would respond to their specific needs.

These community-based initiatives have grown to include 12 centres situated all over the country, and the government is urging BOCAIP to open more centres. From humble beginnings in 1996 with one staff member, one volunteer, and three centres, BOCAIP now has 140 employees on its payroll.

Today, BOCAIP's leadership is composed of representatives of many church denominations across the country. A national management committee oversees the work of the national office, which coordinates 12 counselling centres

throughout the country. These centres in turn have locally elected management committees that represent many church denominations in the community. This local ownership is an important element for the acceptance and efficiency of each centre. The national office, which is based in Gaborone, continues to support the centres and assists in mobilizing resources for their projects.

The counselling centres provide many services. Interested Christian community members, including pastors, are trained in counselling people infected and affected by HIV in a six-week training course spread over about six months. The centres draw their staff from these trained individuals who, in turn, offer counselling to anyone who seeks it, but particularly on issues relating to HIV/AIDS. Training of counsellors is a major part of the service offered by BOCAIP as more and more groups, organizations, government ministries etc. seek to be trained as counsellors.

Other projects BOCAIP undertakes in the centres include education on HIV/AIDS in the community, youth work, support groups for people living with AIDS, income-generating projects, emergency material assistance like food and school uniforms, and orphan day-care projects.

The impact that BOCAIP has had in the community has been so marked that the model is being replicated in other countries, for example, in Liberia. As a result of challenges encountered in the course of its operation, BOCAIP wanted to share its experiences with other Christian organizations responding to the HIV/AIDS pandemic in Africa. This led to BOCAIP organizing and hosting the "Working Together Conference" in June 2002, with 19 countries represented. The participants underscored the need to network and share information and experiences. One of the outcomes of the conference was the formation of the Pan African Christian AIDS Network (PACANet).

Working in HIV/AIDS is difficult and challenging, but rewarding. Finding ways to provide a reason for hope, for living, to someone recently diagnosed as HIV+ requires much prayer and thoughtful counselling. Working with the dying every day is a trying experience which can result in burn-out. Doing prevention education in such a way that today's youth remain uninfected and can marry and raise their own families is a challenge in any community. Giving support and loving care to those infected and ill in a country where stigma still holds a strong grip is an important service. The enormous financial demands for the work beg for sustainability. This would enable the implementers to be free from the need to seek resources. A solution would be to find churches from the West that are willing to twin with BOCAIP and become partners in its activities. Most of all, perhaps, giving guidance and leadership to orphans, who are growing up without parental role models, is what provides the most hope for the future of Botswana.

Notes from the meeting of EHAIA's Interntional Reference Group (IRG)

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The International Reference Group (see IRG composition in EHAIA News No. 1) met from 28-30 September 2004 in Mombassa, Kenya. This was the second meeting. It was, however, for the first time that all appointed Regional Reference Group representatives were present. This included: Edward Baralemwa from the Southern Africa RRG, Loe Rose Mbise from Eastern Africa, Yvonne Kambale Kavuo from Central Africa and Rev. Godson Lawson from the Western Africa RRG. The full EHAIA staff, including the theology consultant and all the regional co-ordinators were also present.

The IRG noted with appreciation the impressive work output reported by the EHAIA staff and their regional representatives. The number of requests made to the theology consultant and the regional co-ordinators seemed indeed overwhelming. The IRG therefore cautioned them to become more focussed and encouraged the RRGs to set reasonable goals for their respective regional co-ordinator, e.g. to initiate activities in a few selected countries. The IRG also took note, with much regret, that the theology consultant, Dr. Musa Dube, had decided to give up her full-time position with EHAIA by end of December 2003 in order to return as Professor to the University of Botswana. A small group of IRG members and WCC staff was formed to give more thought to the way in which this particular aspect of EHAIA work should continue. It was proposed that EHAIA would draw from

the pool of trainers/facilitators that Dr. Dube had trained. This would also enable to have French or Portuguese speaking trainers work in a particular region.

The IRG also discussed the use and need of the EHAIA Newsletter. Since there are many web-sites, discussion groups already available on Internet, is there a good enough reason for the EHAIA newsletter to exist? It was suggested to ask its readers for an assessment in the next edition, January 2004. ***(If you wish to comment on this particular issue, you are most welcome to do so already now.)***

It was again stressed that EHAIA was not to function as a funding agency, but mainly as capacity building programme. However, regional co-ordinators should be in a position to advise or assist those who need help in writing project proposals and who are seeking funds.

The relationship between EHAIA and regional ecumenical bodies was also discussed and the IRG was informed that the AACC has invited EHAIA staff to take an important part in the organization of the HIV/AIDS programme at the upcoming AACC Assembly in Yaoundé, 23-27 November 2003.

The present EHAIA Chairman, Dr. Frits v.d. Hoeven was re-elected by acclamation for the next two-year term.

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