Gender HIV and Human Rights and the Care Economy

Corporate Rights vs Individual Rights

The world of HIV/AIDS is riddled with complexities and dilemmas. In the industrialised world, the discovery of, and a reasonable access to, powerful anti-retroviral drugs have caused death rates to plummet. The same discovery for our brothers and sisters in the developing countries has been rather agonising. “It is like seeing food when you are starving but you cannot eat it.” The fight over these drugs has generated a lot of publicity. What is ironical is that though the development of some of these drugs was funded through public money by some governments, the pharmaceutical companies are today arguing that since they purchased the patents from the governments and invested heavily in clinical trials, it is they who should rightly control the price of drugs and all the more so as the profits feed new research. Corporate rights have therefore prevailed over human rights.

Structural Constraints and Human Rights

Infrastructure and Patriarchy

But as these controversies rage, men and women are coping with some basic structural lacunae as they live with HIV/AIDS. With hospitals running at 170 per cent of their capacity, they are limiting the stay of their patients to two days only. Poverty stricken patients are opting to be discharged as they near death because it is cheaper to transport a person when he/she is alive than it is to transport a dead body. A study in Zambia has recently pointed out that when a patient dies, the family mourns not only the loved one but also the end of food aid.

Men and women in large families living in crowded slums are struggling with the issues of minimum private space to be able to use a condom to have safe sex. Young girls have little or no option to guard their reproductive tracts from sexually transmitted diseases (STDs) with no water available to keep their genitals clean during menstruation. Malnourished and anaemic pregnant women are facing the risks of receiving a transfusion of unsafe blood every time they conceive, deliver or abort a baby.
Care, Rights and the Community

The burden of care and support is intertwined inextricably with a basic human right – the right to live and die with dignity. Are we as communities respecting this right? - a right basic to our existence. Even with no access to drugs in the third world, I can say with certainty that some communities are respecting this right. A community based research undertaken by UNIFEM in Zimbabwe has revealed that as hospital infrastructure is proving to be inadequate and family institutions, both nuclear and extended, are burning out with the burden of disease and sickness, groups of caregivers from the community are springing up to respond to the need of the hour. These caregiver groups are composed of the women of the community, young girls taken out of school to look after patients and some young boys too! With little or no resources available from the city council for the execution of their duties, these groups are improvising and responding on a day-to-day basis. In the absence of gloves and facemasks, they are making do with empty plastic sugar packets. With no linen or soap available from the local government, they are straining their own household budgets to cope with the demands of the disease. From morning till evening they are bathing, feeding, cheering the sick, doing their laundry, talking about death to the children, helping in writing wills, and all this with no monetary remuneration whatsoever.

With little training in home-based care, these caregivers are in fact working in ‘high-risk environments’, with little to protect themselves against infection. And yet when asked what they would prefer, given a choice-to continue caring for the person living with HIV/AIDS in the homes or to put them in institutions – the caregivers immediately responded that they preferred to take care of the patient in his/her home. This, they said, was because the HIV/AIDS patients were not receiving enough care in the hospitals.

Impact at the Macro Level

Zimbabwe offers useful insights for countries on the threshold of the AIDS epidemic. Every indicator of development in this sub-Saharan nation is entangled with the mutating virus. The grip of the virus is pulling it back, away from progress, away from development, away from prosperity. By the year 2010 life expectancy in Zimbabwe will be less by 25 years. The child mortality rate will have been pushed up by 150 per cent. And in spite of these pulls and entanglements, the country has made progress in reducing poverty and in achieving a Human Poverty Index (HPI) value of 25 per cent. The HPI draws attention to deprivation in three essential elements of human life, namely longevity, knowledge and a decent standard of living. The HPI also reveals deprivation that would be masked if poverty were measured only by income. The scales and indices of the UNDP Human Development Report of 1999 clearly show how, amidst such dire threats to development, the Zimbabweans are
moving up in the human poverty index. This indicates that in spite of very little capital availability by way of incomes, and 50 per cent of the population being income poor, in viewing poverty from a broader perspective of longevity, knowledge and a decent standard of living only 25 per cent of the Zimbabweans are poor.

In the light of the epidemic these rather redeeming statistics, brought out in Human Development Report, have been made possible by the work of the caregivers, the women of Zimbabwe, who move like the angels of care, the apparitions of strength who are in fact the shock absorbers.

**Care, Rights and the State**

But as constitutional entities and as governments how far have we moved in honouring the rights and freedoms of people living with the virus or those at risk of HIV?

Dr. X, heading a paediatric section of a hospital in Asia, provided a stark description of the conditions in the hospitals. Working in a ward full of children living with HIV/AIDS, Dr. X had his hands in the air. ‘Shortage of gloves and disposable syringes? We don't even have enough new razor blades to shave the heads of children before setting up a procedure. I don't think people have any conception of the conditions we are working under. We have to perform lumbar punctures and blood transfusions without gloves. And to top the shortages there is the workload, which is ever increasing. We get tired and then we get careless. ‘The laboratories lack the necessary equipment, reagents and skills to make effective diagnoses. Without proper diagnosis treatment becomes difficult and sickness is prolonged. For instance, ‘we often don’t know exactly what is causing the patient’s diarrhoea’.

The implications of this state of affairs for the woman caregivers are enormous. In personal interviews, women have informed us that if the HIV/AIDS patient has diarrhoea, which is a common symptom, they need 23 buckets of water per day to keep him/her clean. Time-use studies have shown that on average a woman requires 45 minutes to fetch two buckets of water in the rural areas of Asia and Africa.

**Rights and Entitlements**

As nation states we have been signatories to a number of declarations, covenants, charters, conventions whereby we have committed ourselves to a people's centred development approach which would ensure that all indicators of development are viewed as entitlements and not as indices for academic discussions only.

- Why is it that the orphans of the AIDS epidemic are being deprived of education?
- Why is it that women are battling with questions as to whether they should risk giving birth to a sick child? Who will care for them? If they do opt for not bringing a sick child into this world who will ensure that they have access to a safe medical termination of pregnancy?

- Why are we converting ‘entitlements’ into ‘services’ and imposing user fees in population struggling with poverty that is getting deep rooted and intragenerational because of HIV/AIDS?

- Why are we supporting / promoting health tourism packages when large numbers of men and women affected by HIV/AIDS are not being able to access basic bandages for wounds, or drying powders for herpes or ORT packages for diarrhoea – the list of opportunistic infections goes on.

The answer to all these posers lies in the fact that we have not been able to make our nation states accountable. We have filled in omissions of good governance by women’s unpaid labour.

**Making Governance Accountable**

How can we make governments more accountable?

1. **Reprioritisation of National Spending** - Perhaps the first and foremost consideration would need to be the reprioritization of our national spending. We need to influence government expenditures in a manner that encourages HIV learning and responses from a human rights perspective. The only agency that has a mandate to examine and enable this to happen is the agency of audit. We need to build the capacity of this agency of change in gender and HIV/AIDS issues; so that the impact assessment that they undertake along with a scrutiny of expenditures, is done within a genderised, HIV sensitive and rights based framework.

2. **Gearing up our social services** - If we are talking here today about gender, HIV and human rights issues we cannot ignore the reality that for woman, a precondition to dealing with HIV is getting other areas of her life in order e.g escaping from abusive relationships. Are our social services geared to facilitate these breakups? In keeping with the constitutional commitments that most governments have pledged themselves to, they would need to respond to the need for more shelters for women in distress, more group housing schemes for women questioning abuse, more centres for child care for working women, more hospitals to cope with morbidity. The natural agency that could legitimately remind the governments about these commitments is the agency of audit. A real acknowledgement of people’s human rights can become a reality with a strong partnership of the offices of the comptroller and auditor generals of the countries.

3. **Redefining development paradigms** - Finally I think the time has now come to redefine some development paradigms. The theory of the triple burden has to now be reconceptualised with the mounting burden of care not just within the household but in the community. We need to begin talking of a quadruple burden being borne by women and in some cases
by men as well. I take to an event during the UN General Assembly’s special session on HIV/AIDS in June 2001. Dr. Mechai Veravidya on the floor of the United Nations declared that there had been a 400% increase in orphans in Cambodia, a 300% increase in Vietnam and Myanmar over the last 3 years and that in his own country, Thailand there were already 90,000 orphans. The projections went on, quoting from empirical analysis recently undertaken by the World Bank in the African region, 1 in every 3 African children were projected to be orphaned by the year 2010. Who will care for them, who will nurture them, who will see that their rights are respected? We will need to re-engineer development through the eyes of these orphans and their carers so that newer options and new vistas are explored and meaning to their lives.

Some options however will need to be closed. Believing that HIV/AIDS is someone else’s problem is no longer an option. The only options are acknowledging that HIV/AIDS is a crime against society; acknowledging that the orphans of the new generation have a boundless horizon before them; acknowledging that the walls of sexual oppression need to be scaled, if not torn down; acknowledging that the way ahead needs to be built on expanded partnerships that are ethically unassailable. Only then will we be able to translate human tragedy to human hope.