Addressing HIV/AIDS from an Intergenerational Perspective

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By: Laura Skolnik

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1. Key issues

In just over 2 decades, HIV / AIDS has permeated borders, crossed continents, and affected individuals, families, communities, and societies across the globe. HIV / AIDS is now recognized as more than just a health issue – it is an issue of development, or economics, of security, and of human rights. In 2001 alone, an estimated 5 million people became HIV positive, 800,000 of them children.

The spread of HIV is due to many, often inter-linked dynamics. These include poverty, low levels of education, gender inequality, population mobility, and lack of access to basic services. Particular vulnerable groups, such as injecting drug users, sex workers and their clients, men who have sex with men, and mobile populations still often lack basic information about HIV / AIDS. Young people around the world also constitute a high-risk group, and lack vital information necessary for protecting themselves.

There exists an enormous civil society "AIDS activism" movement, encouraging political will, implementing prevention campaigns, and providing care and support services for people infected with, or affected by, HIV / AIDS. The global political will to tackle HIV / AIDS has also grown, culminating in the United Nations General Assembly Special Session on HIV / AIDS (UNGASS), held in June 2001. The UNGASS Declaration of Commitment, and later Millennium Declaration, set targets and goals for worldwide action against HIV / AIDS.

The momentous challenge remains for governments to implement measures to meet these targets and goals. In addition, funds need to be raised and resources allocated by the international community. Successful HIV prevention programmes have been identified, and now need to be adapted, replicated and scaled up around the world. Additional emphasis needs to be placed on the provision of care and support service, as well as treatment options. Lastly, partnerships need to be continued and broadened, to include governments, civil society, the United Nations, and the private sector.

The rest of this section briefly reviews the diverse and over-lapping impacts of the HIV / AIDS epidemic.

a) Demographic impact

In many countries, HIV / AIDS is wiping away advancements made in extending life expectancy. For example, in Sub-Saharan Africa, life expectancy is now 47 years, whereas

without HIV/AIDS, it would have been 62 years. UNAIDS estimates that in the 45 most affected countries, between 2000 and 2020, 68 million people will die earlier than they would have. HIV/AIDS has also greatly impacted child mortality – most children who are infected at birth or through breastfeeding will develop AIDS and die by the age of five.

b) Economic impact

The economic impact of HIV/AIDS is diverse and widespread. The epidemic has many employment and labour market implications. Loss of workers to AIDS-related illnesses or caregiving roles leads to productivity decline, loss of earning and loss of skills and experience. Business face increased costs due to absenteeism, recruitment, and staff health care costs. This can reduce international competitiveness and foreign investment. Macroeconomic effects include lower government revenues due to increased health care and social security costs, and lower public demand for good and services.

In the household, families lose income as HIV-positive family members fall ill. Medical expenses increase and other family members may have to be removed from work or school to provide care. After death, family members left behind, such as orphans, widows and older persons face economic uncertainty, which, among other things, increases child labour.

Recently, a World Bank report noted that HIV/AIDS causes greater long-term economic damage to national economies than previously thought.[1] This is because, by killing young adults, the epidemic robs children of their parent(s) who would raise and educate them, thereby undermining the basis of economic growth in the long run. Human knowledge and potential are lost, as children lose access to their parent's skills and experiences, and their own resources are reduced. As these children then grow up, they have fewer skills to raise their own children, and the downward spiral continues.

c) Household impact

As seen from above, the HIV/AIDS strongly impacts on the household in economic terms. Furthermore, the epidemic destroys families, as parent die and children are sent to live with relatives, often grandparents. Roles within the household are reversed, and become confused. Even before death occurs, households suffer greatly, due to loss of stigma and discrimination. Caregivers are less able themselves to work. Families are forced further and further into debt, to pay for care-related costs, to pay for funeral expenses, and/or to take care of orphaned children.

d) Youth

Young people are particularly vulnerable to becoming HIV positive. It is estimated that half of all new adult infections daily, around 6,000, occur among youth. Young people are susceptible due to, among other things, their lack of access to information about HIV/AIDS, lack of access to appropriate health services, and engagement in risky sexual behaviours. Marginalized youth, such as street children, migrants and drug users, are particularly vulnerable as they are often

[1] Long-run Economic Costs of AIDS: Theory and an Application in South Africa, World Bank, June 2003.

excluded from health services. Despite young people's great vulnerability, they are often not taught the proper life skills, including reproductive and sexual health education they need to protect themselves. Research shows that millions of young people have not heard about HIV or harbor misconceptions about how they might become infected.

Furthermore, youth often bear the burden of carrying for family members living with HIV / AIDS. They may have to drop out of school, to care for family members or to earn a living to support HIV-positive family members.

e) Older persons

Growing evidence indicates that older persons are being increasingly infected by HIV / AIDS, with the number of new cases among older women having risen 40% in a recent five-year period. However, data on HIV infection rates among older persons and how older people are affected by HIV / AIDS is still scarce. The most dominant risk factor in people over 50 years is heterosexual sex – the same as for other age groups. Risk factors include not using condoms, due to the view that condoms are only needed as a contraceptive measure. Despite this, older people are consistently left out of HIV / AIDS information and prevention campaigns, due to stereotyping by health care and social service providers.

Older persons are greatly affected by HIV / AIDS, as family structures change. Due to deaths of young parents, grandparents have to provide economic and psychological support to orphaned children. Adequate support, however, does not exist for older family members and grandparents to undertake these roles.

f) Orphans

Currently, approximately 14 million children are living without one or both parents, due to AIDS. This number will continue to rise, as the number of adults dying of AIDS increases. In many countries, with rapidly growing epidemics, the number of orphans will increase dramatically in the future. There are not enough adequate services for these orphans.

Children orphaned by AIDS face substantial stigma and discrimination, in addition to financial hardship as well as the emotional toll of losing a parent(s). Findings show that these orphans are more likely to drop out of school, and engage in child labour activities. UNAIDS notes that there is great concern that these children might become a "lost generation".

g) Other family issues

In addition to the impact on older persons, youth and orphans mentioned above, HIV / AIDS has other profound impact on the family, in both its composition and its welfare. For example, the family unit often has the responsibility for providing care and support to HIV-positive family members. In addition, families with HIV-positive members are often targets of stigma and discrimination. Most noted is also the economic deterioration of the family as a whole that occurs with HIV-positive family members. Family members may have to stay at home to care for others, instead of earning an income of producing food. The discrimination they suffer may prevent them from accessing much needed health and social services.

Gender issues and cultural traditions also have a role. Female family members often bear the brunt of providing care and support for HIV-positive family members, in addition to looking after children and elderly member. Women may also lack empowerment in negotiating roles within the family (in addition to negotiating sexual relationships).

Social, economic, demographic and security concerns are all part of the equation when looking at HIV / AIDS and the family. Despite this nexus, little international attention has been given to researching how HIV / AIDS affects, and is affected by, the family.

2. Project focus

Several perspectives can be undertaken when addressing HIV / AIDS and the family. As reflected in various impacts listed in Part 1 above, HIV / AIDS affects all social groups and socio-economic factors. These include:

1) Role of the family in care and support functions;
2) Orphan crisis; and
3) Threat to the "integrity and functioning of the family"[2].

While all equally important, as is noted in the report on "AIDS and the Family", this last one has received little attention. It would be useful, therefore, to focus DSPD efforts on the impact of HIV / AIDS on the family unit, how it has affected the family roles and intergenerational relationships, and family capital[3].

Although little research has been conducted on the specific topic, the relationships between HIV / AIDS and families are widespread, and contain demographic, social, economic and security issues. These include:

- Circumstances which make certain families more vulnerable to HIV;
- Risk behaviours within the family once a member is infected (including vulnerability of female family members);
- Disclosure of HIV status within the family;
- Redistribution of time and resources (economic, education, health, etc.) to provide care and support functions;
- Effects of stigma and discrimination;
- Neglect of children and older persons (including increased vulnerability of children to sexual exploitation, etc.);
- Disintegration of family after death;
- Role redistribution within the family (such as grandparents looking after grandchildren);
- Effects of a "generation of orphans";
- The extent and functioning of family networks and the community;

[2] "AIDS and the Family: Policy Options for a Crisis in Family Capital", pg. 172.
[3] Ibid., pg. 37. Defined as consisting of three components – relationship, resources and resilience – which are factors affecting the ability of families to cope with HIV / AIDS and related issues.

- Effect on courtship, marriage and death rituals (such as life-cycle transitions).

Family policy should be examined, therefore, in terms of the above-mentioned relationships, which address family factors before a member become HIV-positive, during the time of HIV-positive family members, after the death of such family members. Policies and programmes need to be developed which both support and protect the functioning of families and family capital, focusing on: 1) reinforcing health family relationships; 2) protecting and increasing family resources; and 3) strengthening the resilience of families in changing environments.[4] Specifics might include:

- Prevention policies focused on the family rituals (including the elimination of child marriage, discrimination against girls and women in areas such as property and inheritance);
- Prevention policies focused on reducing risk for vulnerable families (such as general prevention education efforts, VCT);
- Policies to assist and strengthen families with HIV-positive family members (including efforts to extend the productive life for HIV-positive persons, minimize intra-familial transmission, food security and health care issues);
- Policies to lessen stigma an discrimination for families affected by HIV/AIDS;
- Policies to promote and facilitate community support to families affected by HIV/AIDS (such as education and health care subsidies, help in caregiving duties)
- Policies to assist and strengthen families after the death of family members (including food security and education issues, promotion of human rights in areas such as inheritance);
- Overall policies, which protect and strengthen families and family capital (such as income-generation, alleviating the loss of labour, land and capital issues, education, formation of self-support groups for grandparents, youth, orphans, etc. to reduce further vulnerability);
- Policies that support orphans;
- Policies that support organization of people living with HIV/AIDS.

Any focus on HIV/AIDS and the family should also highlight the relationship between HIV/AIDS and the millennium development goals (MDGs). HIV/AIDS is seriously affecting progress toward reaching the MDGs, including the goals to reduce income poverty, reach universal primary education, achieve gender equality, reduce huger, and improve child health.

[4] Ibid., pg. 182.