The number of children affected by HIV/AIDS throughout the world is increasing dramatically and has created what the Joint United Nations Programme on AIDS (UNAIDS) describes as a massive development catastrophe requiring an emergency response. For a variety of reasons, little effective action has been taken to date. There is an obvious need for a greater understanding of the impact of HIV/AIDS on children in order to improve the design and evaluation of programmes to support children affected by HIV/AIDS, their families and communities.

Children affected by HIV/AIDS are defined as children:

- who have HIV
- who have AIDS
- whose parents are sick or have died of AIDS
- whose siblings, relatives or friends have the disease or have died
- whose households are stressed by children from another family who have been orphaned by AIDS
- who are at high risk of infection, such as those who live on the street

The AIDS Pandemic and Children

- An estimated 36.1 million adults and 1.4 million children under the age of 15 are currently infected with HIV around the world, 95% of whom live in the developing world.
- Half a million children under the age of 15 died of AIDS-related illnesses in 2000.
- UNAIDS estimated that by the end of 2000, 13.2 million children worldwide would have lost either their mother or both parents to AIDS.
- More than 90% of children orphaned by AIDS currently live in sub-Saharan Africa.
- According to UNAIDS, the number of orphans will continue to rise, reaching 40 million by 2010. Even if rates of new infections levelled off, mortality rates would not plateau until around 2020 because of the unusually long HIV incubation period. The proportion of orphans will therefore remain unusually high for several decades—at least until 2030.
- In countries where 15% or more of adults are infected, at least 35% of boys now aged 15 can be expected to die of AIDS.

HIV/AIDS is having a disastrous impact on the social and economic development of countries most affected by the pandemic. Some of the most obvious socioeconomic impacts are:

- AIDS-related mortality is leading to plummeting life expectancy and climbing infant and child mortality rates, with life expectancy at birth falling to less than 1950s levels in highly affected countries.
- HIV/AIDS has increased the burden of disease up to sevenfold in highly affected African countries, greatly increasing demand for public health care services, crowding out other conditions and doubling bed occupancy rates.
- AIDS impacts on both the availability and use of schooling. Studies have shown that AIDS causes many children, particularly those who are orphaned, to drop out of school for a variety of reasons (to care for a sick relative, not being able to afford school fees, and so on). Schools are affected as well—AIDS is also killing teachers. In some countries, tenfold increases in teacher mortality and absence due to ill health have reduced teaching time and quality, with each loss affecting from 20 to 50 students. UNICEF estimates that 860,000 children in Africa have already lost their teachers to HIV/AIDS.

Although the economic impact of the HIV/AIDS epidemic is difficult to gauge, mounting evidence suggests that the disease will lead to a significant drop in per capita income levels in Least Developed Countries (LDCs). HIV/AIDS leads to falling labour quality and supply, more frequent and longer periods of absenteeism, and losses in skills and experience, resulting in shifts toward a younger, less experienced workforce and subsequent production shortages. These impacts intensify existing skills shortages and increase training costs and benefits. They are felt throughout the economy from the macro-level to the household.

Recent studies have shed light on the impact of AIDS on food security in highly impacted countries. They show that HIV/AIDS reduces food availability (through falling production, loss of family labour, land and other resources); access to food (through declining income for food purchases); and the stability and quality of food supplies (through shifts to less labour-intensive production).

The effect of HIV/AIDS on households is profound. Lost income and the diversion of assets to caring for those affected impoverishes families. AIDS causes labour to be lost or diverted from production to care. Household incomes fall due to loss of wage earners and rising spending, particularly on medical care and funerals. AIDS also generates new poverty as people lose housing.
tenure and employment. A study in Zambia found, for example, that AIDS led to a rapid transition from relative wealth to relative poverty in many households. In two thirds of families where the father died, monthly disposable income fell by more than 80%.

In human terms, the impact of HIV and AIDS on affected children poses serious threats to child welfare. The problems and needs of affected children are summarized as:

- psycho social distress
- discrimination and stigmatization
- increased malnutrition
- lack of security
- lack of parental guidance
- loss of access to health care, including immunization
- increased demands for labour
- fewer opportunities for schooling and education
- loss of inheritance
- homelessness, vagrancy, starvation, crime
- exposure to HIV infection and other STDs
- sexual exploitation, either commercially or at home

Selected Policy and Programming Issues

A child whose mother or father has HIV begins to experience loss, sorrow and suffering long before the parent's death. And since HIV can be spread sexually between father and mother, once AIDS has claimed one parent, the child is far more apt to lose the other. Children therefore find themselves taking on the role of a parent—performing household chores, caring for siblings, farming, caring for ill or dying parents—creating stresses that would exhaust even adults.

Because HIV infection progresses from initial infection to mild HIV-related illnesses to the life-threatening illness called “AIDS,” children can live with long periods of uncertainty and intermittent crises, as both parents slowly sicken and die. Children who live through their parent's pain and illness frequently suffer from depression, stress and anxiety. And once the parent(s) die(s), children often endure grave social isolation while experiencing intense grief.

The literature on children affected by AIDS is replete with observations to the effect that children in these circumstances suffer adverse psychological consequences and that they have a “need for” or a “right to” psychological support. There is, however, a dearth of substantive research and understanding of effective policy and programmatic responses to the psycho social needs of children affected by AIDS, particularly in developing countries.

Children’s Rights to Participation

Many international non-governmental and key community-based organizations working in the area of children affected by HIV/AIDS are in the process of moving away from a “needs-based” framework to a “human rights-based” framework to guide their policy and programming. The United Nations Convention on the Rights of the Child (CRC) sets out the political, civil, cultural, economic and social rights of children, and serves as one of the guiding documents for governments and non-governmental organizations which aim to ensure the rights of children in the context of the AIDS pandemic.

A rights-based approach to programming is a relatively new concept—as with all new approaches, it will take time to educate practitioners and to “learn by doing.” The efforts of non-governmental and community-based organizations to help actualize the rights of children to participate in the formulation and implementation of HIV/AIDS strategies, programmes and policies have been hampered by a dearth of resources. Duplication of successful programmes has been restricted by a lack of information.

Culturally Appropriate Participation

One of the key lessons learned by practitioners working to facilitate the participation of children is that the process often entails educating and building the capacity of the community with respect to children's rights and responsibilities. This involves exploring with the community how they perceive children's participation within their culture and coming to an understanding of how a child's right to participate can be actualized appropriately within the culture.

Definition of Orphan

UNAIDS defines AIDS orphans as children who lose their mother to AIDS before reaching the age of 15. Consequently, orphan statistics do not include children who have lost only their fathers, or children between the ages of 15 and 18. Also excluded from this definition are non-orphaned children living in households that foster orphans.

Many question the relevance of the UNAIDS definition as it fails to recognize many of the children rendered vulnerable by the pandemic. This failure means that current UNAIDS estimates and future projections of the number of children orphaned by AIDS grossly underestimate the scope of the impact of the disease on children.

A recent study (Monk, February 2000) conducted among 152 households in nine rural Ugandan villages yielded compelling evidence in support of those in favor of a more inclusive definition of orphan. The study expanded...
the definition of orphan to include children who have lost their father, mother, or both, and included children up to the age of 18.

The study also included non-orphaned children who were living in households that foster orphans. The research showed that one of the most vulnerable groups of orphans was paternal orphans—who are not included in the UNAIDS definition of orphan.

Of the 152 households interviewed, only two indicated that there were differences between the way orphaned and non-orphaned children were treated. In each of the other 150 households, all children were treated the same regardless of biological parentage or duration of stay. Therefore, the numbers of children living in orphan-fostering households is a more accurate reflection of the true extent of the orphan crisis than the numbers of orphans alone.

If the UNAIDS definition is used to enumerate orphans in the research area, 279 children are identified. If a more inclusive definition of orphan is used, the number rises to 1,386 AIDS-affected children: an increase by a factor greater than four.

Obviously, an expanded definition of orphan and a greater emphasis on “vulnerable” children as opposed to “orphaned” children has profound policy and programming implications for all stakeholders in responding to the needs of AIDS-affected children.

**Gender Issues, Policy and Programming**

All members of society are vulnerable to the impact of HIV/AIDS, but not equally so. Women and children—particularly girls—and the elderly are most vulnerable. Consequently, the analysis and integration of gender concerns into policies and programmes is an essential step in strengthening the effectiveness of the responses to AIDS.

Examples of the gender dimensions of AIDS in the area of children affected by AIDS:

- Globally, more than half of all new HIV cases occur among young women and men aged 15 to 24. In Africa, an estimated 1.7 million young people aged 10 to 24 are infected annually. In a number of communities, researchers have found that young women (including girls) are more likely to be HIV-infected than men and boys their own age. For example, in Kisumu, Kenya, 22% of women aged 15 to 19 tested positive for HIV, compared with 4% of males in the same age group.

- A number of factors—social, cultural and biological—contribute to the greater vulnerability of girls to HIV. Young women may be at a disadvantage in negotiating condom use or the fidelity of their partners because of age differences, economic disparities, and gender norms.

- In general, very young women are often more prone to STDs than adult women because of the immaturity of their reproductive organs. In some studies, HIV transmission is more efficient from men to women, indicating that women may be more biologically susceptible to HIV than men.

- Evidence of the impact of AIDS on children's school attendance also indicates that girls are more likely to have their education disrupted than boys, and girls are more likely than boys to be expected to take over household and caregiving chores when a parent or guardian becomes sick with an AIDS-related illness.

- The care for children orphaned by AIDS is increasingly falling to the elderly—primarily women—in severely impacted countries and communities. In Zimbabwe, for example, where 26% of all adults are infected with HIV, a government-sponsored survey in three rural communities found that of 11,514 orphans, more than 11,000 were being cared for by relatives, most of whom were poor women, widowed, and over 50.

Organizations working in the area of children and families affected by HIV/AIDS accept the need to integrate gender concerns into the planning, implementation and evaluation of their programmes. Many NGOs, however, lack the knowledge and tools to do so effectively.

**Scaling Up the Response**

In 1998, a new emphasis in the discourse and literature on HIV/AIDS took hold: the need to “scale up” to expand programme and policy responses to problems caused by HIV/AIDS by governments, donors, international and local NGOs. The new emphasis on scaling up the response was brought about by a growing awareness that existing responses were inadequate to deal with the magnitude of the problem.

Actual achievement of effective scaling up has been almost nonexistent—while it has been a useful concept for advocacy purposes, it has not been applied to a significant extent because of associated costs. Moreover, there are too few documented examples for policy makers and programmers to emulate.

The most systematic study of scaling up, to date, has been conducted by the Horizons Project of the Population Council. At the time of writing, only limited information on Horizons' work in the area of scaling up is publicly available. It is expected, though, that additional information and resources will be released in late 2001.

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