CHILDREN IN FAMILIES AFFECTED BY THE HIV EPIDEMIC:
A STRATEGIC APPROACH

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This paper is a part of a series being issued by UNDP and UNICEF in collaboration with UNAIDS. These publications are an element in the 1997 World AIDS Campaign which has as its theme "Children Living in a World with AIDS". The purpose of the papers is to raise issues relating to children and families affected by the HIV epidemic with the intention of raising awareness of the complex and difficult problems now faced by many countries.

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INTRODUCTION

The concept of families is an important analytical and programming tool which is often overlooked within development theory and practice. Children do not spring untrammelled into the world. They are born with ties of blood, love and law to their families: parents, brothers and sisters, grandparents and other family members. These ties can bind generations together into a supportive and nurturing unit which provides security, care and love to its members. The ties change over time, maturing, strengthening and weakening. Such ties may be created and recreated outside of lineage groups, by street children, by adoptive families and by others.

Many of the most striking images of the HIV epidemic are of families, but of unfamiliar families: a grandparent surrounded by grandchildren, adolescent-headed families, often siblings and cousins bonded together, dying adults tended by their children and communities as families. It is timely to focus on such families rather than on children alone, or youth alone or adults. This allows for an intrafamilial and longitudinal analysis of the needs, skills and resources of families affected by HIV which provides a different basis for determining and ranking the required responses.

This analysis has already been done by a number of organizations assisting adolescents and children whose parents know they are HIV-infected, are ill or have died of AIDS. There is much to learn from them and this paper attempts to draw together some of their insights and knowledge. These programmes teach us that careful attention is needed to understand the trauma of children watching their parents sicken and slowly die and how this experience affects their long-term development. Attention is also needed to understand how the families and communities caring for these children can be supported in sustainable ways to continue providing care to them and how the capacity for self-support of surviving families of children can be strengthened.

The forms that families take vary within and across cultures and generations. They are affected by increasing urbanization, by poverty, by political and economic migration, by changes in labour market structures, by the changing roles of women and other factors. Superimposed on all these factors now will be the impact on family life of the death of many parents and young adults.
Most of those infected are in the age group 20 to 40 years and the overwhelming majority are parents. Furthermore, the overwhelming majority of all those infected do not know they are infected. Many women are indirectly diagnosed when they are still well through the diagnosis of HIV infection in their children. Many men do not get diagnosed until they have a clinically observable HIV-related illness. In most households where there is one infected person, there will probably be three or more: both parents and one or more children.

WHO estimates that eight million adults in Africa have been infected with HIV and so possibly four million families already know that they are affected or will soon know. Many of these affected families do not cease to exist when the adults die. They live on as grandparent or adolescent-headed families, but many of them are seriously distressed, destitute or scattered. The figures for other developing regions and Eastern Europe are still much lower but in many areas are growing rapidly.

Up until now, many of the policies and programmes addressing the needs of affected children and adolescents have assumed that these needs start with the death of their mothers or parents and consist of predominantly material needs. It is important to broaden this focus. This paper argues that the needs of these young people start with the knowledge that someone in their family is infected and continue on to their social and sexual maturity. Their needs are psychological, emotional, ethical, legal and spiritual; they are for acceptance, nurturing, support, counselling and care; they include financial, material, educational, health and social development needs.

The paper also argues that the needs of these children cannot only be met by policies and programmes addressed to children and youth. There are at least three other types of interventions required: assistance to their parents, to their communities and of their governments. For the well being of their children, parents need to be able to continue working, need to be assisted in planning for their and their children's future and need access to treatment of opportunistic conditions which may lessen their ability to work and parent.

Extended family systems and communities need support in keeping these new family forms in their midst. Governments have a multifaceted role in increasing awareness, establishing an appropriate legal, ethical and human rights framework and in the provision of the required services and support.

This paper is intended to raise a number of issues which can serve as a basis for widespread discussion. It is addressed to all those interested in determining how best to respond to the epidemic. It is not a Manifesto for Children and Youth but rather another way of looking at the complex reality of this epidemic and its exigencies which may enable individuals, organizations and nations to rethink their HIV-related policies and programme priorities. It is now starkly clear in many parts of Africa that, if we do not quickly find appropriate ways of responding to this epidemic, the lives of many future generations will be bleak, anguished and often brutal.

**PROGRAMME ELEMENTS**

While specific programme components will vary according to the stage the epidemic has reached and the situation, culture and resources of each country or community, five main strategic programme elements can be identified. Under each programme element, a number of programme components have been identified. These are not meant to be exhaustive nor are they operational in nature. The specific means of addressing each area may vary from one situation to another.

Certain components may already be included in a national response but may not have been seen to have linkages to the well-being of children in affected families. Other components may not yet have been put in place. The analysis here can provide a basis for reassessment of programme priorities, both at the national level and in community organizations.

1. Preparing Children for the Future
Most parents come to know they are HIV-infected when one of them or one of their children is clinically diagnosed with HIV-related illnesses. The earlier a parent’s infection status is known, the more time he or she will have to plan for the children's future, in particular to find another family or person who can care for and shelter them. The parent will also have more time to pass on their skills and knowledge to them, to help the children be able to support themselves. Knowing their infection status when they are well will help the parents prepare their children and themselves emotionally for their deaths. The longer a parent can work and the longer he or she can be helped to stay well and nurture and raise the children, the less pain and trauma the children will experience.

Components of this programme element could include:

- **Access to voluntary, confidential and affordable counselling and testing for adults and the motivation to use it.** This would allow parents more time to plan for their own and their children's future. Infected parents often want to seek advice on how and when to tell this to their children. Supportive services and counselling can help parents maintain a nurturing home environment for their children as long as possible and to find future homes for them. Access to testing and counselling can also assist people in making decisions about whether they wish to have more children.

- **Disclosure with counselling of a child's infection to both parents.** The Women and AIDS Support Network Conference in Zimbabwe in 1989 stressed the importance of both parents being informed at the same time if that child is infected and that both receive caring counselling regarding their child's and their own HIV status (1). In some cases where a child has been clinically diagnosed with AIDS and only the mother has been informed, the father has blamed the mother and abandoned her and the sick child.

- **Continued employment.** HIV-infected people who remain fit to work have the right to remain employed. If this right is denied them, their children will suffer.

- **Simple treatment of opportunistic infections.** Experience in Masaka, Uganda and Kigali, Rwanda has shown that, for many HIV-infected parents, treatment of conditions such as thrush, skin infection, diarrhoea and fever is important since it allows them to continue to work, to nurture their children and to die with dignity (2). Providing such treatment can often help parents to remain with their children for a longer period. The parent's suffering is eased and the children's memories of their parent's dying can be made much less traumatic. Counselling and access to appropriate low-cost or subsidized medicines may lessen the problem of families exhausting their resources in a futile search for a "cure".

- **Passing on to children production- and income-generating skills.** In Uganda, the Kitovu Hospital home care team encourages parents, once they know they have been infected with HIV, to pass their production- and income-earning skills on to their children (3). In addition to helping the children to become economically independent, it can also be of emotional benefit to an infected parent who, through teaching them these skills, can do something to help their children.

- **Planning for children's future care.** The emotional stress of both parents and their children can be eased through parents planning for the future care and support of their children. The importance of this has been stressed repeatedly by infected women in all parts of the developed and developing world. Once the future guardian is identified, financial, legal and other arrangements can be made and this person or family involved in planning for the children's future.

- **Protection of children's inheritance and other legal rights.** The children's continuing access to the family house, land and goods is critical to their survival and well-being. Specific steps appropriate to traditional inheritance customs and/or national law may need to be taken by parents before their deaths. Discussing inheritance matters with clan elders and/or preparing and registering a will are examples. Parents need to be informed about their legal rights in relation to property ownership and how this can be passed on to the surviving spouse and children.

- **Prevention of infection while caring for the sick.** The experience of the
home care and counselling teams of Chikankata Hospital in rural Zambia shows that simple techniques can minimize the likelihood of children or other family members being infected while caring for the sick and dying (4).

2. Assisting children whose parents have died

Children whose parents have died of HIV-related illnesses have often also lived through the deaths of others close to them: brothers and sisters, aunts and uncles, cousins, friends and, increasingly, grandparents. Their very will to live has often been undermined. If they are to grow and develop as human beings and as members of civil society, they need love and care and the opportunity to form and maintain emotional ties with adults. Their material and psychosocial needs will have to be met; their right to remain integral members of their communities and their legal rights may be at risk and need protection. Consideration can be given to the provision of services to all children within an area heavily affected by the epidemic rather than only to those whose parents have died of AIDS. The latter approach may lead to resentment and stigmatization of children who receive targeted assistance.

Components of this programme element could include:

- **Minimizing children's psychological and emotional trauma.** The grief and loss for all living within this epidemic can be overwhelming but may be particularly so for children who watch their family members die one after another (5). Such children not only suffer emotional pain but may also experience long-term psychosocial distress. Grief and depression may be evident or they may be expressed through behavioural problems. Children need opportunities to express and come to terms with these losses. Loving care and support can help heal the pain. Play is another important way that children do this. Experience with traumatized Mozambican refugee children, and in villages in Masaka and Rakai districts in Uganda, has shown that community-based activities such as play groups can help children recover. Normalization of daily life, like continuing to attend school, is also important. Teachers, religious leaders, nurses, healers or other adults in the community can be trained to counsel and help children recover from trauma.

- **Keeping survivors as integral members of their communities.** This will necessitate attitudinal change where discrimination and stigma toward survivors exist. It will also require the provision of care and shelter within the children's families or communities. One significant advantage of care within the children's own community is that relationships can be maintained which will be important as the children grow older. Children cut off from these relationships will have no one to turn to when help is needed. Where discrimination and stigma cause the isolation or rejection of children whose parents have died of AIDS, political and community mobilization for the protection of their customary, legal, ethical and human rights will be particularly important.

- **Basic material needs.** Direct assistance is often required by affected families. Women in Kigali asked Caritas to help them continue to be able to care for their children as long as possible by providing a nutritious meal for them and their children each day and by treating the opportunistic infections that hindered their ability to care. TASO in Uganda (6), WAMATA in Dar es Salaam and the Kagera region (7) provide food and blankets and, at times, financial assistance. The basic needs of affected families need to be met on an ongoing basis.

- **Education, training and employment creation.** Formal education, vocational training, non-formal skills training and the provision of necessary tools and equipment can help children support themselves. In addition, such measures as public works programmes, revolving credit schemes and other measures to create employment can benefit children directly or through the families caring for them. Day care facilities, formally or informally arranged, can free time for work while ensuring that young children are cared for. Young people who have lived through the trauma of this epidemic often have knowledge, skills and insights that could help other young people in similar situations. Opportunities could be created for them, for example, by apprenticing them to traditional...
healers or through working in outreach programmes to newly affected children.

- **Children's social and adolescent's development needs.** To grow and develop into an adult capable of constructive social interaction, children need to be nurtured and stimulated. Younger children, for example, develop best when they have an opportunity to establish an ongoing, caring relationship with one or more adults. Such developmental needs have important implications for the type of care appropriate to provide for children and adolescents whose parents have died. Family-based care in a child's own community generally provides the best opportunities for promoting positive psychosocial development.

- **Children's and adolescent's sexual development needs.** Sexually active adolescents generally lack access to information services for sexually transmitted infections and to condoms, particularly sizes to fit boys. They also lack opportunities to discuss these issues with each other or others whom they respect. The Anti-AIDS clubs in Zambia or the discussion groups run by the Women and AIDS Support Network in Zimbabwe have shown that providing these opportunities can significantly change peer group sexual norms, expectations and behaviour.

Children and adolescents who have cared for and then watched the adults in their lives die one by one and who know that these deaths are linked to the expression of sexuality may well experience problems as they move into puberty and into adulthood. There is no precedent for the extent or types of these problems. Community workers, religious leaders and others will need to be aware of these possibilities and keep communities aware of what is happening.

**3. Meeting the special needs of HIV-infected children**

As with adults, most asymptomatic HIV-infected children do not know that they are infected. They continue to lead their daily lives. Simple infection control procedures can protect all family members or institutional workers from transmission of the virus. Testing has been advocated both mandatory and voluntary to determine the HIV status of orphans. However, there are serious ethical issues involved in testing and disclosure to children. Issues which need to be determined include: Who wants to know and why? Will it benefit the child to be tested and know? How? Who should determine this and how? Can a child give informed consent to testing? Public policy needs to be drawn up in this area.

Infants and children with HIV-related illnesses may have special care needs. Meeting these is more difficult where one or both of the parents is also infected or has died.

Components of this programme element could include:

- **Support to families with a sick child.** One of the most effective ways of supporting a sick child is by providing support to the family caring for it, particularly by helping them deal with the trauma of the diagnosis. An infant with an HIV-related condition like many other sick children often suffers from chronic diarrhoea, fever and respiratory infection. As with adults, however, the provision of a healthy diet and basic medications can improve the quality of its life. A child's illness may be the first indication to its parents that they are infected with HIV.

- **Promotion of non-discrimination policies and programmes.** Enforcement of existing laws or establishment of new ones may be necessary to ensure the rights of HIV-infected children. For example, inheritance laws, both customary and modern, may have to be reviewed or enforced to ensure that infected children have access to their parent's property for support, adoption laws may need to be made more flexible to facilitate care for their children and anti-discrimination laws will need to be established and/or enforced. Creating a community environment where HIV positive children can be placed with families can help reduce discrimination against these children. Families of children with an infected child should be supported if they desire to stay together.
4. Reaching children and adolescents who are especially vulnerable

Among and within families affected by the HIV epidemic, there will be some children or families of children at particular risk of destitution and of HIV infection: urban families without the support of their extended families, families who for whatever reasons lack the support of their communities, children struggling to survive on the streets, children suffering sexual abuse within families, and others. For many of these young people, survival sex, sex in exchange for money, clothing, affection, shelter, food, etc., is a basic coping strategy.

Components of this programme element could include:

- **Assistance to street children.** Special strategies need to be developed to help children living on the street to have greater control over their lives, to have the means to avoid infection and to seek alternatives to the street. Street children and others living in marginal circumstances may not only be isolated from the wider community, they may be actively persecuted by it. Providing a broad range of measures to help increase their safety, health and well-being may help reduce their social marginalisation.

- **Reducing the susceptibility of young women to infection** (8). Girls and young women may be particularly susceptible to HIV infection not only because they are less able to control the situations in which they have intercourse but also because their genital area provides less of a barrier to the virus and is easily irritated or torn. Communities and families need to assist young women to wait longer before becoming sexually active and to be able to ensure that all their sexual activity is safe.

5. Reducing the number of affected children

This objective can be achieved by decreasing the number of adults becoming HIV-infected. Highest priority must be given to bringing about the attitudinal and behavioural change and the change in community norms and values required to bring this about. Because those with less control over their own lives are at greater risk, efforts to improve the socio-economic status of the most destitute and measures to empower women are critical to reducing the spread of the virus.

**PROGRAMME STRATEGY**

The breadth and diversity of the interventions required to respond adequately to the needs of children in families affected by the HIV epidemic present particular challenges to programme development and implementation. If the five programme elements just outlined are to be achieved, there must be an overarching programme strategy which is to create an environment that will encourage and support the necessary changes.

In this respect, policies to address the needs of children in affected families are no different from those directed, for example, to adults. Efforts must be made to create an environment that is sensitive to the needs and concerns of all people affected by the epidemic and which expresses care and compassion for these people rather than fear, hostility or alienation.

1. **Assess needs, monitor the situation and its impact**

In areas seriously affected by the epidemic, the ability of extended families and communities to provide for the basic needs of children without parents may be threatened. Those from outside the community who wish to provide support should, as an initial step, seek to understand what specific difficulties these children, families and communities are facing and how they themselves are coping with them. Cultural and socio-economic differences will result in different patterns of need as well as
different survival and coping strategies both within and among communities and countries. These variations need to be taken into account in planning interventions so that the measures carried out will reinforce and not undermine constructive family and community level efforts.

An inventory and/or needs assessment can provide an initial picture of the situation of children in families affected by HIV. A system for monitoring needs and measuring the impact of interventions over time needs to be established. It can generally best be established by building upon existing systems functioning at the village level and above, such as village health or development committees or health posts. Assessment and monitoring are most effective when they are participatory processes, actively involving people from the communities most affected. Participation in assessing and monitoring needs also creates local awareness and engagement.

2. Create national awareness and engagement

There is a need to sensitize the public to the specific needs and problems of children in families affected by the epidemic as well as to promote a national sense of responsibility for responding to these needs. The extent and nature of the situation need to be widely understood and people committed to respond to it. The government, private organizations, non-governmental organizations, faith communities and international organizations can all help create an environment that will facilitate appropriate responses to these children.

3. Develop a national policy framework

The social, legal, ethical and human rights framework of the national response as well as its administrative and coordination arrangements need to be in place as early as possible. The national policy framework will guide and support appropriate responses to the needs of children in affected families from the local to the national levels. Policy areas could include: measures to protect the rights and prevent discrimination against affected children and their families; the availability of affordable voluntary counselling and testing; a national drug policy that ensures the accessibility and affordability of the basic medicines needed to treat opportunistic infections; non-discriminatory personnel policies which enable infected persons to continue to work; the rights of affected families to medical benefits and insurance.

The Government of Malawi has developed a policy framework to guide responses to the needs of affected children (9). These establish priorities for action and define which types of services are appropriate and which are not. Existing policies and legislation should be reviewed to determine their direct or indirect impact on the well-being of affected children and on the capacities of families and communities to care for them. Some governments have waived school fees for children whose parents have died. In some cases, governments have defined clear policies regarding the kinds of services that can be provided to limit the diversion of resources into well-intended but inappropriate interventions.

4. Create consensus on the most effective and sustainable responses

The epidemic is a new and complex phenomenon and the most effective way to respond may not be known or be widely accepted. There could be conflicting and different approaches proposed. It is important that there be widespread discussion leading to acceptance of and support for appropriate initiatives. The affected communities together with other sources of expertise should assist in the development of such a consensus. The process of consensus building will create a broader base of support if all the key actors take part and thereby develop an investment in implementing the agreed upon policies.

External support for initiatives that are not consistent with the agreed approach can be harmful. Families and communities will play critical ongoing roles in meeting the needs of affected children. Well-intentioned agencies can create problems by funding interventions that bypass or supplant these roles. It is much more difficult to try to re-
establish spontaneous family and community systems of care than to support them initially.

5. **Develop mechanisms to ensure resources are used effectively and equitably**

Mechanisms may be needed to promote the equitable distribution of external support and to ensure that it meets local and national needs and priorities. These may be needed at both the district and national level. One example is the Uganda Community-Based Association for Child Welfare (UCOBAC), which is a consortium of local and international child-focused organizations (10). It has been instrumental in creating awareness of the problem, in facilitating the coordination of activities, organizing training for the staff of member groups, promoting appropriate policies and standards of care, organizing research and monitoring children's needs. UCOBAC has also established a grants bank to help ensure available donor resources are used where most needed and in appropriate ways.

6. **Strengthen national capacity to implement the programme**

Implementation requires adequate expertise, funding and clarity about roles. Governments may find, where resources are limited, that their most effective role is guiding service providers and donors regarding priorities established in the policy framework and monitoring changing needs and programme results. Bureaucratic impediments to supporting needed services should be minimized and interventions inconsistent with the national policy framework should be pre-empted. Raising public awareness and developing a consensus on needed responses can help mobilize local participation, probably the most important resource needed. Training is a crucial element in further developing capacity to respond effectively.

**CONCLUSION**

The ways in which HIV is transmitted ensure that, at least in the initial stages of its spread in a given country, some communities will be affected earlier and more intensely than others. It is important from the outset that the problems emerging and the services required be seen as national priorities and not just concerns of the localities and groups first affected. Equitable burden sharing is needed.

Likewise, within the most affected communities, the tendency is for women to be faced with a disproportionate burden for the care, nurturing and raising of affected children. Encouragement for men to share and alleviate these responsibilities should be built into programmes.

Families and communities are the first to respond to the need of children in affected families. Consequently, government and agency policies and programmes to benefit these children will need to focus primarily on how they can support families and communities to provide for their needs. The emphasis will be on supporting, and where necessary, establishing, sustainable family and community-based efforts. For this to happen an enabling environment is required in which public awareness and government policies and programmes include the full range of children's psychological, social, material, legal and spiritual needs.

**ENDNOTES**


2. Sr. Ursula Sharpe of Kitovu Hospital in *The Orphan Generation*, Uganda, Small...

3. The Orphan Generation. op. cit.


10. Information on the Ugandan Community-Based Association for Child Welfare can be obtained by contacting UCOBAC in Kampala, Uganda at +256-41-255-828 or by fax (c/o UNICEF) at +256-41-259-146.

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