

Gilborn, L. Z; Nyonyintono, R; Kabumbuli, R; Jagwe-Wadda, G. 2001. *Making a difference for Children Affected by AIDS: Baseline Findings from Operations Research in Uganda*

Many organizations provide support services to children affected by AIDS in East and southern Africa. Yet few of these programs have been evaluated. In Uganda, PLAN International, Makerere University, and the Horizons Program are collaborating on a study to assess the impact of an orphan support program on the physical, educational, and emotional well-being of children. The researchers are also studying a different program, called succession planning, in which children are reached before the death of the parent. This intervention includes helping parents to write wills and appoint guardians, creating family “memory books,” and other activities that promote the long term well-being of children. The baseline sample includes 353 parents who are HIV-positive, 495 children of people living with HIV/AIDS (PLHA), 233 orphans, and 326 current and standby guardians.

Key Baseline Findings

The impact of adult illness on children starts when a parent is diagnosed as HIV-positive or becomes ill with HIV/AIDS. Earlier research demonstrates that children orphaned by AIDS suffer physical, educational, and emotional setbacks. Baseline data from the current study demonstrate that these setbacks begin *before* parental death. For example, older children of PLHA (n = 181, ages 13-18 years) report a decline in school attendance (26 percent) and performance (28 percent) when parents became ill.

Property grabbing is widespread, with women and children especially vulnerable.

Among widows (n = 204) in this study, 29 percent say that property was taken from them when their husbands died, making them four times more likely than widowers to have experienced property grabbing. In addition, 21 percent of older orphans (n = 105, ages 13-18 years) report experiencing property grabbing. This phenomenon further undermines the livelihood of households that are already weakened by the death of adult breadwinners. Despite valid concerns about property grabbing, only 10 percent of parents in this study have prepared written wills.

Many guardians are in poor health, and some are even infected with HIV/AIDS. Of the 51 guardians in this study who know their serostatus, one-third reports that they are HIV-positive. Among parents who have not appointed a guardian, some report that the person they have in mind is HIV-positive, old, sick, or “likely to die before I do.” As many as 40 percent of the HIV-positive parents in the sample look after orphans, meaning that they themselves are HIV-positive guardians. With elderly relatives and others in poor health comprising the “safety net,” it is likely that many children will lose not one or two but a series of caregivers and relatives.

Most older children want their parents to tell them the truth about being HIV-positive.

Most older orphans who know that a parent died of AIDS say that parents should disclose their own serostatus to their children. Parents are also predominantly in favor of disclosing their HIV status to their children, but the majority (57 percent) have *not* done so, with many reporting uncertainty about how to discuss the topic. Parents and children who are in *favor* of disclosure say they feel this because they value honesty, talking about prevention, and being able to plan for the future.

Study participants say that material support is what they need most. When asked what they need in order to look after their children and foster children, both parents and guardians are most likely to say that they need material assistance or support.

Selected Program and Policy Recommendations

Reach children affected by AIDS before they become orphans. This research demonstrates that children living with HIV-positive parents need as many support services as orphans who live with guardians. One way to reach children early is to link programs for children affected by AIDS with care and support programs for PLHA. This link also strengthens the responsiveness of care and support programs by addressing a top concern of PLHA: the future well-being of their children.

Increase community awareness and accountability about the property rights of women and children. Although writing wills is not traditional in East and southern Africa, doing so may reduce property grabbing. However, the impact of will writing will be limited unless communities, leaders, and policymakers mobilize to uphold the property rights of women and children. National and religious inheritance laws may need to be enacted or strengthened. The International Convention on the Rights of the Child (signed by most African nations) is another useful tool for advocates of property rights for women and children.

Address the critical health needs of adult caregivers, including guardians. This study demonstrates that *guardians*, as well as HIV-infected parents, have critical health needs. Life prolonging care and support services for adults may minimize the toll of adult illness on children, increase the ability of adults to care for the children, and prolong critical adult-child relationships.

Improve capacity for adult-to-child communication, especially about difficult issues such as sex education, and parental illness and parental death. Parents and guardians say they need support and advice on how to discuss these difficult issues with children. It is important to respond to this demand because the psychosocial needs of these children are often overlooked. Older children benefit from honest disclosure of parental illness. Programs should explore ways in which parents, guardians, teachers, and religious leaders can develop adult-to-child communication skills.

Address material needs in AIDS-affected households. HIV-positive parents and guardians say that they urgently need material help to support their dependents in the face of illness. This support can take the form on income-generation projects, vocational training, food, clothing, home repairs, and the payment of school fees.
