

HITTING HOME
How Households Cope with the Impact of the HIV/AIDS Epidemic
A Survey of Households Affected by HIV/AIDS in South Africa

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Executive Summary

This report summarizes the results of a survey of 771 AIDS-affected households in different parts of South Africa. The households were randomly selected from the client lists of non-governmental organizations providing support to AIDS-affected households in the regions where the survey was conducted. The survey and this report are an attempt to document the impact of HIV/AIDS on South African households. Although it is not representative of all AIDS-households in South Africa, the report provides a snapshot of the devastating impact of HIV/AIDS on already poor families. As bleak as the findings of this survey are, the households in this survey are likely better off than most since all households in the survey had contact with non-government organizations providing support to HIV-affected households.

No sector of the population is unaffected by the HIV epidemic, but it is the poorest South Africans who are most vulnerable to HIV/AIDS and for whom the consequences are inevitably most severe. The average age of the AIDS-sick person in the households surveyed was 35 years—in most cases these were breadwinners and the parents of young children. This report illustrates that in already poor households HIV/AIDS is the tipping point from poverty into destitution.

This report documents the impoverishing impact of HIV/AIDS on households and the inordinate burden of caring for AIDS-sick family members. It also documents access to and satisfaction with public services, as well as access to government financial support for AIDS-affected households.

Children are the worst affected

Forty four percent of the households in the survey had monthly income less than R1000. Two thirds of these households reported loss of income as a consequence of HIV/AIDS. Increased expenditure on medicines and medical care, and the high costs of funerals are also contributing to

the financial burden. Among the most profound consequences of AIDS-related illness and death, and the resulting erosion of household income are:

- Almost a quarter (22%) of all children under 15 years in households included in the survey had lost a parent.
- More than two thirds (64%) of the AIDS-sick individuals in the survey were female on average 33 years of age.
- Increasing childhood malnutrition—almost half of the households in the survey reported having insufficient food at times and that the children in these households often went hungry.
- The break-up of families—more than 12% of households had sent their children away to live elsewhere, most often with a grandparent or another relative.
- Increasing childhood malnutrition—almost half of the households in the survey reported having insufficient food at times and that the children in those households often went hungry.

The burden of care

The households worst affected by HIV/AIDS are also those most underserved by basic public services such as sanitation and piped water. Only 43% of households in the survey had a tap in the dwelling and nearly a quarter of the rural households in the survey had no toilet at all. These harsh circumstances substantially add to the burden of caring for an AIDS-sick person, as well as the patient's suffering and loss of dignity:

- 68% of the caregivers in the households surveyed were women or girls—7% of them younger than 18 years and 23% older than 60 years.
- One in six of AIDS-sick individuals in the households surveyed could not control their bowels and about the same number could not control their bladders. About 20% could not wash without assistance.
- More than 40% of households reported that the primary caregiver had taken time off from formal or informal employment or schooling to take care of the AIDS-sick person adding to the loss of household income and the under-schooling of girls.
- Households reported that on average the AIDS-sick person was chronically ill for a year before dying.

Government grants are not getting through

The households surveyed for this report are the lucky ones in as much as they are all receiving some level of assistance from non-governmental organizations including help in accessing government grants. Even though all the households in the survey were eligible for at least one form of government grant, fewer than 16% of households were receiving government grants of any kind.

- Only about 10% of households reported getting home-based assistance from government welfare services.
- Eighty percent of households used public clinics, but 50% reported that they also used private doctors.
- About 40% of respondents who used public health services said they were less than happy with these services. The reason most often given for this dissatisfaction was the uncaring attitude of health workers and inadequate treatment ranging from medication that did not work, to the lack of beds for the chronically ill and early discharge of ill patients.

Denial is Still Widespread

Only about 50% of the households in the survey said that the sick person they were caring for had HIV/AIDS. Most often respondents only mentioned opportunistic infections such as tuberculosis and pneumonia. But where respondents had revealed the AIDS-related cause of their illness, families tended to be supportive.

- About 80% of those who had been open about their HIV status said that the household had been very supportive. Hostility from family members was rare.
- But only 35% of those who had revealed their HIV-status reported a supportive response from the community. One in ten reported hostility and rejection.
- Of those in the survey who said they had been employed at the time of their HIV diagnosis, half said that their employer had been very or fairly responsive. Eight percent said their employers had responded unfairly or with hostility.

Conclusions

This report confirms what perhaps is already obvious: that poor people in South Africa are the most adversely affected by HIV/AIDS, that the public health service is struggling to satisfy the medical

needs of AIDS-sick patients, support to AIDS-affected these households is limited and available government grants are not getting through. But it also points to some of the more profound longer term ramifications of the HIV epidemic:

- deepening poverty among the already poor;
- disruption and premature termination of schooling for children, especially girls;
- increasing early childhood malnutrition;
- and increasing strain on extended family networks.

Although most respondents in the survey had little difficulty accessing clinic-level care and were generally pleased with the service they received, more sick patients are routinely referred to district hospitals. Respondents were substantially less happy with the service received at district hospitals mainly because AIDS-sick patients are only kept in hospital a short time and the lack of appropriate treatment. Terminally ill AIDS patients are generally sent home to die and access to home-based care programs is very limited. AIDS-affected households are spending up to a third of their income on private medical care. The lack of AIDS treatments in the public health system together with the lack of home-based care and support is further exacerbated by difficulties in accessing available government grants.

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The Henry J. Kaiser Family Foundation, based in Menlo Park, California, has since 1987, maintained a program in support of South African efforts to establish a more equitable national health system. An important part of this effort is providing information and analysis on health issues to policymakers, the media and the general public.