

Using rapid research to develop a national strategy to assist families affected by AIDS in Tanzania



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Abstract

Although information on African family adaptation to the AIDS epidemic is critical to planning and managing government, donor and NGO programs of assistance, current knowledge is limited to a small number of research studies. An AIDS prevention project in Tanzania undertook a rapid national assessment to identify the major problems for families in Tanzania in adapting to the epidemic. The methodology used for the work was distinct from prior studies: the research covered a wide cross-section of Tanzanian population groups to gauge the extent of ethnic, urban-rural and regional variation; it was rapid and qualitative, to gather data on broad trends in a short time; and it was designed in co-operation with policy-makers so they could understand the approach being used and were receptive to the findings. The study identified common problems in AIDS care, counselling and survivor assistance. Many of the problems for families with AIDS have their origin in poverty and changes in African family structures over the past 20 years, which African demographers are just beginning to describe. Stresses arising from these changes are now being aggravated by AIDS, but families with sufficient resources, whether female or male-headed, are coping better than those without.

Background

In 1994, the Tanzania AIDS Project (TAP)¹ conducted a National Assessment of Families and Children Affected by AIDS (NAFCAA) in conjunction with three Tanzanian ministries, three local training institutes, and one UN agency². The assessment was a rapid, one-time baseline of eight regions of

¹The Tanzania AIDS Project (TAP) is a five-year, \$20 million project signed by the United States and Tanzania Governments in July 1993. The Project's goal is to reduce the impact of AIDS on Tanzanian society by reducing the HIV transmission rate and the social and economic consequences of the epidemic. TAP is one of the first US-funded AIDS projects to include programs to alleviate the social and economic effects of AIDS on individuals, communities and families in Africa. The main TAP strategy is to rely on and enhance local capacity to implement long-term interventions directly with businesses and non-governmental organizations who organize, co-ordinate, and fund their own activities.

²Ministry of Labour and Youth Development, Social Welfare Division, the National AIDS Control Programme of the Ministry of Health, the Ministry of Community Development, Women and Children, UNICEF, the National

Tanzania which are home to 48 per cent of the country's total population, 29 ethnic groups, and more than 50 per cent of the country's orphans. In addition to the NAFCAA, TAP completed a baseline study of non-government and community resources in each region. The full Demographic Health Survey STD/AIDS module was also completed in 1994, expanding the range of information for planning, management and evaluation.

A 1993 project design paper for TAP suggested that families affected by AIDS and children orphaned by the epidemic would need long-term assistance in many regions of Tanzania (Fleuret 1993). Because there is little information on family adaptations to the epidemic in Africa and in Tanzania (except for Kagera Region), organizations, including TAP, that want to assist families are developing programs in the absence of clear data or government guidelines to help them determine the practicality or acceptability of long-term community-based strategies.

Given this need for information, the AIDS Project developed the concept for the NAFCAA with Ministry and academic collaborators in late 1993 and early 1994. The research protocol had to be rapid, capture accurate overview information useful for program design and modification, and be economical because of project budget constraints. The Assessment gathered information in four areas: family systems for caring for the AIDS-afflicted and their survivors; children's problems and needs; institutional, community and family resources; and multisectoral government and non-government organization activities. The final document profiled comparative research, policy and program initiatives in other countries to determine if NAFCAA findings were coherent with earlier work.

The main purpose of the NAFCAA was to develop observations for use in program design and to stimulate policy dialogue and development. According to one NAFCAA researcher,

there is a feeling among social workers and health workers that the pace of the pandemic is not being matched by efforts made. No government ministry is able to cope with the epidemic's growth. The National AIDS Coordinating Committee is doing its best, but the pace of the epidemic calls for more government planning to deal with the increasing number of AIDS affected families and orphans. This would entail a clear policy and strategy formulation (NAFCAA, Morogoro).

AIDS in Tanzania

By the end of 1994, there were a total of 53,247 AIDS cases reported in Tanzania, an estimated one-sixth of all cases in the country. This was 15 per cent of the total reported to WHO from Africa. In Tanzania, the National AIDS Control Programme (NACP) estimates that there are 1.6 million HIV-positive persons, 14 per cent of the African total estimated by WHO. Ten to 15 per cent of Tanzania's urban population and three to six per cent of the rural population are infected. Rates among antenatal clinic attenders are as high as 30.4 per cent in some locations in Western Tanzania, where infection rates are higher. This is the non-circumcision zone of the country, part of the belt running from Uganda through Burundi and Rwanda down through Tanzania, Zambia, Malawi and Zimbabwe (Caldwell and Caldwell 1993). By 2000, there will be more than 800,000 AIDS cases, 2.4 million HIV-positive Tanzanians, and one million AIDS orphans in Tanzania. The male-to-female case ratio is 1:1, although seroprevalence is higher among females (7% of blood donors compared to 5% among men). According to the NACP, the case data are skewed because men are more likely to be taken for medical treatment.

Family research on AIDS in Sub-Saharan Africa

Social Welfare Training Institute, the University of Dar es Salaam Faculties of Law and Sociology, and the Muhimbili University College of Health Sciences. TAP has co-ordinated its work with other organizations collecting related information (World Bank, World Health Organization, and UNICEF) so a shared national data base can be developed. Other potential partners are the Ministry of Education, the Planning Commission, and the Social Workers Association of Tanzania.

In 1993, a survey of research on family responses to AIDS concluded that existing knowledge

originates with a small number of researchers who have examined a limited number of cases....A great deal is being written but much of it is based on the continuous recirculation of a small number of research findings (Caldwell et al. 1993:236).

The data base for the research surveyed was 306 households in Uganda and Ghana (Hunter 1990; Ankrah, Lubega and Nkumbi 1992; McGrath et al. 1992; Barnett and Blaikie 1992; Anarfi 1992a, b). Five studies not included in this summary have examined the effect of AIDS on agricultural production and household economic strategies (Hunter, Barton and Sserunjogi 1992; Hunter, Bulirwa and Kisseka 1993; Ngasongwa et al. 1993; Drinkwater 1993; Barnett 1994; Topouzis 1994). The data base for the first two studies included 326 households in Uganda; the latter four studies used rapid rural appraisal, including key informant interviews and focus-group discussions. Findings from three studies involving more households (Medical Research Council, Masaka, Uganda; World Bank, Kagera, Tanzania; Centre International de l'Enfance in Ivory Coast, Burundi, and Haiti) are not yet published. Although they involve many more households, their relatively small geographic coverage limits their ability to detect variation caused by evolution of epidemic mortality, socio-economic conditions, or ethnic variations in family adjustments.

Many aspects of African family organization condition family response to AIDS, including descent lineages; the value of children; polygyny; age at marriage; labour migration and urbanization; cohabitation and marital formation and dissolution (divorce and widowhood); economic control of women by men; household division of labour; child care, fostering, and orphan care; increased poverty. The inter-country variations of these characteristics have been preliminarily explored using World Fertility Survey and DHS data (Page 1989; Lloyd and Desai 1991; Desai 1992; Bruce and Lloyd 1992; Bruce, Lloyd and Leonard 1995), but not referenced in AIDS-related studies.

AIDS research to date shows that the locus of patient and survivor care is the family, because of poverty, lack of institutional care, and personal preference. However, changes in family composition and increasing poverty are hindering the family's ability to provide care according to cultural ideals of altruistic behaviour. Most patients care for themselves or are assisted by female relatives, whose isolation is increased because of the time needed for care and by AIDS stigma. Caretakers often lack medicine or treatment to alleviate symptoms and opportunistic disorders. Family neglect results from lack of money and competing demands on caregivers, who need social and psychiatric support and community education to reduce stigma, blame, and isolation.

Families and communities often face additional problems arising from AIDS prevention campaigns, which challenge traditional African family beliefs, promote Western styles of marriage (monogamy, faithfulness, strong partner bonds), and empower women at the expense of spousal relations and male responsibility in family care. HIV testing may have ambiguous benefits, protecting some partners but creating problems for others and increasing the amount of time HIV-positive people live with fear, guilt and stigma. In areas with high AIDS mortality, farm families have suffered labour losses, and responded with changes in land ownership and use, food and cash-cropping patterns, food storage, and livestock holdings; the result is diminished adult and child nutrition.

In areas with polygyny, there are twice as many paternal as maternal orphans, but the proportion of double orphans in any population increases with epidemic mortality. Since the probability of orphaning increases with age, more orphans are 5 - 9 and 10 - 15 than 0 - 4 years old. Orphans are cared for by grandparents, uncles, aunts or their own siblings. Female orphans are preferred as domestic labour, for sexual diversion, or for their bride price when marriageable. Research findings comparing the condition of orphans and biological children are contradictory, but some studies show that orphans are more likely to be removed from school because of loss of household income or the need for agricultural labour, and experience higher mortality and morbidity, and poorer nutrition. Young children with mothers missing are most likely to suffer additional morbidity and mortality.

Family research and policy studies in Tanzania

Since 1990, several general studies have been completed on families and AIDS in Tanzania, all based on field research in Kagera Region, bordering Uganda. The findings are similar to those of the studies summarized above. Increased AIDS mortality has increased the burden of survivors, while medical and burial costs have diminished family resources. Ironically, labour shortages were creating opportunities for people of traditionally low status (youth, women) to engage in non-traditional roles (Kaaya 1995). Orphans needed food, shelter, clothing, shoes, soap. Their access to education and health care had diminished, and they were more prone to malnutrition and other infections. The children also needed support for psychological and bereavement problems.

Findings from more detailed household studies conducted in Mwanza (Netherlands), Arusha and Kilimanjaro (Norway), Dar es Salaam (Duke University), and Mbeya (WHO) are not yet available. There have been four district or regional enumerations of orphans in Tanzania (Mutebei 1988; Evangelical Lutheran Church 1989; Rwegarulira and Mushi 1991; Mushi 1990). These are maintained, but have not been analysed demographically. UNICEF's 1990 *Women and Children in Tanzania: A Situation Analysis*, based on 1988 census data and other research, related recent trends in family destabilization to the continuation of plantation agriculture, geographic concentration of industrial production, and recent economic declines resulting in labour migration, and worsening health, education, communication and information services. Poverty correlated with nutritional level, and infant, child and maternal mortality. Areas dependent on food crop production are more vulnerable because of difficulties in generating additional cash income. Growing poverty has eroded community responsiveness and elasticity, and emergence of multi-party politics has eroded the citizen's relationship to local political and social infrastructure.

Female-headed households have lower incomes, less access to food, smaller average land holdings, less agricultural or supplementary labour, and less planted acreage than male-headed households. Women cultivators and their children, the majority of both population groups in Tanzania, have lower survival rates than other occupational groups. Women whose husbands migrate for work or who are the sole earners in their households need especially strong support systems to assist them in meeting household and agricultural labour demands and generating additional income. Women's literacy is higher (81%) than men's (55%), and female primary school attendance is higher, but their secondary attendance is slightly lower. Despite these advances, the social position of women is low. Land use is controlled by men. Women have use rights only, and allocation of land to women by village governments is rare. While women often control the disposition of food crops, sale and profits of cash crops are controlled by men. Children are the property of the husband and his family, and only very young children may stay with their mother in the event of marital breakup. Property may be claimed by the husband's family as repayment for bride price.

Special tabulations of the 1991/92 Tanzanian Demographic and Health Survey (DHS, Ngallaba et al. 1993) provided the following information:

Fostering

Fostering children is common in all regions of Tanzania. A total of 23.1 per cent of Tanzanian households include foster children under 15 (without their mother, father, or both parents present). Some 34 per cent of Tanzanian children under 15 are fostered (living without one or both parents), and 11.5 per cent are without either parent (Table 1). These include children whose parents have died as well as those whose parents are missing for other reasons. A higher proportion are missing their father (28.5%) than their mother (17.5%). These figures vary widely by region, and bear no obvious relationship to orphaning or AIDS mortality. Other cultural forces are at work, suggesting that in regions where fostering or adoption are commonplace, they may be handled more routinely. The proportion of children whose mother or father is absent from the home is at the high end of the range reported for African countries by DHS (Bruce et al. 1995:85-87). Most foster-children with mother

absent live in households headed by their father (83%), the remainder in households headed by a grandparent (Table 3a). However, more than half of the children without their father live with a grandparent or another relative. Grandparents are also the predominant caretakers for children with both parents missing (59%).

Table 1
Proportion of children under 15 with mother, father or both parents absent by study region

Region	Mother absent		Father absent		Both absent		Total		Total children under 15
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent	
Arusha	147	11.6	292	22.7	93	7.2	348	27.1	1285
Dar es Salaam	195	21.0	268	28.9	109	11.8	354	38.2	926
Dodoma	265	18.3	374	25.9	178	12.3	461	31.9	1447
Iringa	144	11.7	361	29.4	114	9.3	391	31.9	1228
Kagera	335	22.3	367	24.4	211	14.1	491	32.7	1502
Morogoro	161	15.2	362	34.1	113	10.7	410	38.7	1061
Mwanza	332	23.6	428	30.4	224	15.9	536	38.0	1410
Tanga	154	14.5	324	30.5	94	8.9	384	36.2	1061
Total	1735	17.5	2776	28.0	1136	11.5	3375	34.0	9918

Source: Ngallaba et al., 1991/92 Demographic and Health Survey

Orphaning

A total of 14.3 per cent of Tanzanian households include children with one or both parents dead (Table 2). Of these, 7.1 per cent have maternal orphans (mother dead), 11.6 per cent have paternal orphans (father dead), and 4.4 per cent double orphans (both parents dead). By region, the proportion varies from 15.1 to 39.4 per cent. A total of 10.8 per cent of children under 15 in the national DHS sample were orphans, 3.9 per cent maternal, 7.7 per cent paternal, and 0.8 per cent double. If applied to national population estimates, a total of 1,230,789 children were orphans in 1991. This is nearly double the proportion of children orphaned estimated from 1988 census data (Ainsworth and Rwegarulira 1992). Regional rates vary from under 5 per cent to more than 11 per cent, and do not correspond to patterns of AIDS seroprevalence or deaths. The causes of this variation have not yet been established. Most maternal orphans live with their father (53%) or a grandparent (23%). Paternal orphans live with their mother or a grandparent (64%). Double orphans are taken in by their grandparents (42%) or another relative (41%), although almost 12 per cent are cared for by an older sibling (Table 3b).

Table 2
Proportion of children under 15 with mother, father or both parents dead by study region

Region	Mother dead		Father dead		Both dead		Total orphans	Total children under 15	Per cent
	Number	Per cent	Number	Per cent	Number	Per cent			
Arusha	28	2.2	82	6.4	9	0.7	101	7.9	1285
Dar es Salaam	20	2.2	45	4.9	3	0.4	62	6.6	926
Dodoma	31	2.1	37	2.6	4	0.2	64	4.5	1447
Iringa	13	1.1	69	5.6	0	0.0	82	6.7	1228
Kagera	50	3.3	99	6.6	5	0.3	144	9.6	1502
Morogoro	43	4.1	60	5.7	6	0.6	97	9.1	1061
Mwanza	47	3.3	79	5.6	22	1.5	104	7.4	1410

Tanga	29	2.7	40	3.8	4	0.4	65	6.1	1061	5.49
Total	261	3.9	511	7.7	53	0.8	719	10.8	6646	5.31

Source: Ngallaba et al., 1991/2 Demographic and Health Survey

Table 3a
Distribution of fostered children under 15 by relation to household head

Relationship	Mother absent		Father absent		Both absent		Total	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Head	0	0.0	0	0.0	0	0.0	0	0.0
Wife or husband	0	0.0	0	0.0	2	0.1	2	0.0
Son/daughter	785	83.0	938	36.8	9	0.5	1733	32.2
Grandchild	114	12.0	961	37.7	1121	59.4	2195	40.8
Brother/sister	0	0.0	25	1.0	81	4.3	107	2.0
Other relative	44	4.6	461	18.1	613	32.5	1118	20.8
Adopted/fostered	2	0.2	127	5.0	6	0.3	135	2.5
Unrelated	3	0.3	33	1.3	55	2.9	91	1.7
Total	946	100.1	2549	99.9	1887	100.0	5380	100.0

Source: Ngallaba et al., 1993, Demographic and Health Survey

Table 3b
Distribution of orphaned children under 15 by relation to household head

Relationship	Mother dead		Father dead		Both dead		Total orphans	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Head	0	0.0	0	0.1	0	0.0	0	0.1
Wife or husband	0	0.0	0	0.1	0	0.0	0	0.1
Son/daughter	84	52.5	151	44.6	0	1.3	236	44.0
Grandchild	36	22.5	72	21.2	14	41.8	122	22.8
Brother/sister	6	4.0	27	7.9	4	11.6	37	6.9
Other relative	28	17.4	67	19.8	14	40.5	109	20.3
Adopted/fostered	1	0.8	13	3.9	1	2.6	15	2.9
Unrelated	4	2.8	8	2.5	1	2.2	14	2.6
Total	160	100.0	339	100.1	34	100.0	535	100.0

Source: Ngallaba et al., 1993, Demographic and Health Survey

Household characteristics

Other household characteristics which affect care for persons with AIDS and their survivors also vary widely by region (Table 4). Household size varies from 4.0 to 7.1 by region, averaging 5.3 countrywide and being largest in rural areas. The proportion of households which are female-headed declined from 30 per cent in the 1988 Census to 19 per cent in the 1991/2 DHS survey. This is in the middle of the range reported for Sub-Saharan countries by the DHS (Bruce et al. 1995:16-17). Countrywide, approximately twice as many women (27.5%) are in polygynous marriages as men (16.1%). Regional rates for men range from 5.3 to 32 per cent, and for women from 12.2 to 48.9 per cent. Most women (65%) live with their husbands or partners, although rates also vary by region (50% to 74%). This is correlated with the proportion of women ever married, widowed, or divorced. On a national level, 7.1 per cent of all women are divorced (3.1% to 12.2% by region). Marital patterns relate to the population

age structure, sex ratio and migration patterns. Iringa has the lowest ratio of men to women (0.87), the largest proportion of female-headed households (27.1%) of any region, some of the most deeply entrenched poverty, and one of the highest HIV seroprevalence rates in Tanzania.

Table 4
Household characteristics by region

Region	Per cent Households with female heads	Per cent Never married females 15-44	Per cent Men in polygynous unions	Per cent Women in polygynous unions	Average household size
Arusha	17.5	25.9	25.3	31.1	5.2
Dar es Salaam	17.0	30.2	2.6	12.4	4.4
Dodoma	23.6	23.3	16.1	18.8	4.7
Iringa	27.1	20.4	32.3	34.8	4.9
Kagera	14.1	27.2	12.9	19.7	5.6
Morogoro	18.7	22.2	5.3	22.5	5.4
Mwanza	13.2	23.6	9.6	31.2	6.6
Tanga	21.5	23.2	16.7	28.5	4.9

Sources: 1988 Census; 1991/2 Demographic Health Survey

Nutrition, health and education

Overall, 7.1 per cent of all Tanzanian children and 9.7 per cent of adult women are severely malnourished (Table 5). Regional rates of child and adult malnutrition do not correspond. Regional variation is wide. Severe stunting ranges between 9.7 and 32.7 per cent and severe wasting from 0.4 to 3.2 per cent. Some 71.1 per cent of all children are fully vaccinated: 47 to 88.6 per cent by region, with ten regions exceeding the national average. Mothers' reports of diarrhoea range from 6.1 to 23.3 per cent by region. Infant and child mortality rates vary by zone, urban-rural residence, and mother's education. Overall, 37.4 per cent of females and 48.4 per cent of males over age five have no education. Paternal orphans are disadvantaged, but for most age groups, educational status is better for double orphans (Figure 1). Maternal orphans appear to get a later school start, but differences disappear in the 10-to-14 age group.

Table 5
Selected ethnic and socio-economic indicators

Region	Ethnic groups included in NAFCAA	Male to female ratio (1)	Per cent males 5+ with no education	Per cent females 5+ with no education (2)	Per cent children <5 fully vaccinated (2)	Per cent children <5 severely malnourished	Per cent women 15-49 with low body mass index (2)
Arusha	Arusha, Chagga, Irqw, Masai, Meru, Songo	1.026	43.0	44.5	59.3	5.2	16.4
Dar es Salaam	Mixed	1.110	21.9	32.2	77.4	4.0	5.8
Dodoma	Burunge, Gogo						
	Sandawe	0.935	43.0	49.8	82.4	7.2	7.5
Iringa	Hehe, Bene, Pangwa	0.878	36.3	52.0	75.1	13.2	6.8
Kagera	Hangaza, Haya, Shubi , Subi, Zinza	0.960	36.0	50.1	74.7	6.0	10.6
Morogoro	Gogo, Masdai, Sagara, Uluguru	0.982	35.9	50.5	77.2	7.8	9.2
Mwanza	Jita, Kara, Kerewe, Ruri, Sukuma	0.999	39.4	49.9	61.5	5.3	6.9
Tanga	Bondei, Digo, Sambiaa, Zingua	0.954	31.3	42.5	67.5	6.1	12.5

(1) Source: 1988 Census; (2) 1991/2 Demographic Health Survey

Conclusions

A review of the literature on family response to AIDS in Tanzania and other African countries reveals the following.

(1) All but two of the previous studies are based on limited fieldwork in two Ugandan districts and one contiguous Tanzanian region, an area with small ethnic and linguistic differences and frequent intermarriage. Thus, they cannot be construed as representative of Sub-Saharan Africa or Tanzania.

(2) Results of three detailed, longitudinal (3-to-5-year) studies of family adaptation are not yet available. Two were completed in the same areas of Tanzania and Uganda as already published work, and will not expand on geographic coverage.

(3) Family adaptations to labour and income losses evolve in relation to the family's mortality experience, and local mortality and morbidity rates.

(4) Changes in Sub-Saharan African family structure have been occurring over the past several decades, including increases in single-parent families and fostering. Existing research on family adaptation to AIDS does not address these changes, which can be documented in existing data-bases, and may unwittingly attribute continuing family changes to the epidemic.

(5) Women bear most of the responsibility for care of patients and orphans, but are not cared for well themselves when they fall sick. They fare better if they can maintain their property and retain their children.

(6) The orphaning rate in Tanzania is almost twice what it was in 1988 estimates. Orphans may be faring relatively well in areas with external assistance, but are disadvantaged educationally and nutritionally in areas with high mortality.

(7) Extrapolation of study findings to policy applications were few.

Method

To overcome the limitations of previous research, the NAFCAA was designed to be both national and rapid, the first simultaneous assessment of variations in AIDS adaptations across cultural groups in many regions of a country. In addition, findings of the rapid qualitative studies were interpreted in the context of existing statistical data to relate AIDS-related adjustments to continuing social change. Lastly, policy-makers were included in the process of research design and assisted in interpreting findings and developing recommendations for improvement. Findings are also being shared with non-government organization leaders in each of TAP's regions of operation.

Eight regions of Tanzania were selected to maximize potential variation in the stage of the epidemic (AIDS case rates, HIV seroprevalence, orphan rates), and ethnic contrast: Arusha, Dar es Salaam, Dodoma, Iringa, Kagera, Morogoro, Mwanza, and Tanga (Table 6). Four regions have high HIV seroprevalence estimated from blood donor data (Dar es Salaam, Iringa, Kagera, Tanga), and four have relatively high orphaning rates (Iringa, Kagera, Morogoro, and Tanga). Household characteristics affecting AIDS care also vary widely in these regions. Within the regions, research sites represented intra-regional diversity relevant to family and individual AIDS coping strategies and resources (urban-rural settlement type; environmental, economic, and agricultural zones; ethnicity).

Research strategies were designed to collect information on the **economic, social and cultural context** of family and individual coping, including household size and composition, marriage formation and dissolution, bride price, the value of children, inheritance, and conditions of fostering and orphanhood, income levels, crops, animals, businesses, migration and trade patterns, labour requirements and productivity, availability of education and health resources, and environmental stresses, and the impact of AIDS in the region; and on **current coping strategies of individuals and families**, including the numbers, locations and circumstances of AIDS sufferers and orphans, family experiences with AIDS victims and orphans, community, NGO and government responses and support,

differences between cultural ideals and family realities, and family and institutional arrangements for care.

Table 6
Population and AIDS data for eight regions in NAFCAA

Region	1991 Population (1)	National rank	1994 AIDS cases (2)	National rank	1983-1993 average blood donor seroprevalence rates for females	National rank
Arusha	1,629,389	5	1,599	16	3.6	16
Dar es Salaam	1,694,822	4	10,213	1	12.5	3
Dodoma	1,430,024	8	765	20	4.0	14
Iringa	1,395,133	10	2,853	6	10.8	5
Kagera	1,536,065	6	5,116	3	11.8	4
Morogoro	1,423,004	9	2,572	9	5.4	12
Mwanza	2,187,890	1	3,535	11	6.3	10
Tanga	1,470,324	7	2,136	12	7.6	7
Subtotal	12,766,651	-	28,789	-	-	-
Total mainland Tanzania	26,358,373	-	53,247	-	7.0	-
Study area as per cent of total	48.43	-	54.07	-	-	-

(1) 1994 data extrapolated from 1991 figures using 2.5% annual growth rate. Source of 1991 data: *Tanzania in Figures*, Tanzanian Bureau of Statistics; (2) Source, all AIDS data: National AIDS Control Programme, Ministry of Health, Tanzania.

Researchers gathered basic socio-economic data on the regions, and used two methods, key-informant interviews and focus-group interviews, to gather data on individual and family strategies and resources. Types of informants and focus groups were specified in advance, and protocols drafted for each type to encourage uniformity of data collection across all regions. Researchers conducted interviews with regional and district government officials and community leaders in major urban centres. Urban and rural focus groups were organized with health-care workers, primary and secondary school teachers, male and female elders, orphan care-givers and orphans. Where appropriate, individual interviews were conducted with persons with AIDS and their families and survivors.

The NAFCAA research team included one American and five Tanzanian social scientists from anthropology, sociology, history, political science, linguistics, and public health. Fieldwork for the institutional and ethnographic assessments was conducted in six regions in May and June, 1994, and the remaining two in October.

The principal advantages of the research approach was its rapidity, economy, and ability to reveal inter-regional and inter-ethnic patterns in AIDS-related problems and coping behaviour. This made it easier to identify national patterns, and long-term trends, and envisage future adjustments and support. The major disadvantages of this approach arose from the limited field period. Researchers spent only ten days in each region. While they completed what they could of the protocol, in most regions many targeted individuals and groups were not interviewed or convened.

Findings from the national assessment

NAFCAA's observations are consistent with the findings of prior studies and assessments of programs in Tanzania and other Sub-Saharan African countries. They are reported below in six categories: family

life; care for persons with AIDS; assistance for orphans; community responses; residence and ethnicity; and government roles.

Family life

AIDS-related social problems are growing quickly and creating profound demands and social stresses on families and communities across Tanzania. Although there is regional variation, generalizations are possible.

Geographic variation

The variation in distribution of HIV infection rates, AIDS mortality rates, and related social problems is high, even across small geographic distances. Most heavily infected are cities, towns, and places of commerce, where the social problems faced by families and children affected by AIDS are likely to be worse because people are mobile and lack family support. Lay consciousness of AIDS and its attendant social problems is low, while health-care professionals, government workers, and NGO representatives are reasonably well-informed. Few elders and community leaders are aware of pending social problems, although community awareness increases directly with mortality.

Socio-economic trends

Researchers found it difficult to separate AIDS-related family problems from those caused by other conditions. Changes in family structure originate in historical patterns of labour migration and long-term economic trends which have left more families vulnerable to HIV infection and less able to cope with long-term illness, medical costs, or support of orphans and foster-children. An Assistant Social Welfare Officer in a medium-sized Tanzanian city reported that the problems of children living in poverty, with single mothers, from broken homes, or living on the street, are increasing. Many are the victims of parental abandonment or death, abuse by step-parents, neglect, and hunger. This official averaged two support or abandonment cases per day, and found men often had second wives and girlfriends whom they were treating as badly as their first. Although it has become popular to say that AIDS is destroying the extended family system in Sub-Saharan Africa, it may simply be hastening its evolution. Before AIDS the extended family was stressed and changing in response to many trends which are not short-term and cannot necessarily be addressed in AIDS-related programming.

AIDS-related problems

However, AIDS mortality and morbidity create distinct, additional, stresses on families, including changes in family roles and relationships, emotional strain and instability arising from extended illnesses and multiple deaths; sudden financial drains from diagnosis, treatment and funeral expenses; loss of external income from wage labour or trading; household and agricultural labour loss and declines in agricultural productivity, income, nutritional and educational status for widows and their children; and stigma, affecting the person with AIDS, family members and children.

Effect on women

Female-headed households comprised 12 to 27 per cent of Tanzanian households by region. These figures do not account for households in which women are the *de facto* heads, such as polygynous households. Women provide subsistence and care in the majority of households they do not head. Female-headed households are especially vulnerable because they are poor and their economic options are limited: beer brewing, food preparation, bar work, petty trade for those with some capital. Payment

for sexual activity with non-regular partners is more common among women who are not currently married, although the mean number of sexual partners is lower (Tanzania Bureau of Statistics 1995). When a woman becomes pregnant, unless the man responsible agrees to marry her, she risks being disowned by her relatives. A number are moving into urban areas as a result:

Single mothers are on the increase as a result of changes in social norms pertaining to sex and the family. They live a lonely life and their children grow up without relatives apart from their single mothers. When such young mothers die, as indeed many of them have, their surviving children are truly destitute orphans, bereft of any familial relations. Sometimes children of divorced mothers face similar difficulties (NAFCAA, Kagera).

Women in Tanzania are more affected by the epidemic than men. They often cannot protect themselves from infection. A 1994 DHS survey found that 31.4 per cent of men aged 15 to 49 had non-regular sexual partners compared to 7.3 per cent of women in the same age group (Tanzania Bureau of Statistics 1995). A woman whose husband has other partners can do nothing about it, and looks the other way when her husband acquires a girl-friend. When infected, husbands can expect their wives will care for them, while women who are infected are often abandoned by their male partners, relatives, and in-laws, and have less access to the formal health care system. A NAFCAA interviewer in Ilula, Iringa was told of a woman who died by the side of the road waiting for a ride to the regional hospital because she did not have the money for bus fare. Women are denied access to land ownership, and lose their property after their spouses' death. Protection of property rights is critical to family well-being, because widows who retain their property can continue to raise food, keep livestock, and feed their children.

One woman has lost a husband and child over the course of the last two years. She has three remaining children: one eleven, one eight, and a small, sick baby. Her oldest has only just started school. While her husband was sick there was no one to care for him. She has no family because her own parents died long ago. She has one sister who lives in a village about 60 kilometres away. She herself is ill. She started being sick at planting time. She was not able to plant her normal amount and now is worried about her harvest. The house and *shamba* she uses belongs to her husband's family and they are allowing her to use it but they offer her no other help. They are poor themselves. Village leaders are very worried about her (NAFCAA, Iringa).

The focus-group discussion involved 11 women, ten of whom are AIDS widows and the eleventh a single mother of one child who is also caring for five children left by her sister and her husband, both of whom died of AIDS in 1992 and 1993. Two of the women have full-blown AIDS. Between these eleven women, there are a total of 56 orphans, an average of five per caregiver, with the following distribution: two women are caring for one child, four are caring for three to five children, and five are caring for seven or eight. The burden on these women is quite considerable, especially since all of them are desperately poor. Only one is in formal employment as a telephone operator. The majority are doing some kind of petty trading. One earns her living by breaking rocks into gravel, one is a dress maker and the two who are suffering from AIDS are too sick to do anything meaningful. Three of the women have had problems with in-laws concerning inherited property. One, a mother of seven, who has a running court case over inherited property, has, along with her children, been evicted from her matrimonial home by her late husband's relatives.

Only two of the women live in their own homes. The rest live in rented housing or with relatives. One, who is quite sick, is virtually homeless and has been temporarily taken in by several friends. Three of those in rented accommodations owe several months' rent and one of them is under eviction

notice from the landlord. The majority of women are caring for their children single handedly. Only 6 of the 56 children are under the care of relatives, all of them women. None of the widows receives any cash support from anyone. When asked why their relatives or their deceased husbands' relatives did not render assistance, most replied that the relatives themselves were desperately poor. All ten widows knew they were HIV positive. They expressed extreme anxiety about the future education and housing of their children, which they invariably described as absolutely bleak (NAFCAA, Mwanza).

The burden on children

Those suffering without respite from AIDS are the children of those afflicted, who have watched their parents die, sometimes nursing them alone. Many children have severe psychological problems as a result. Their basic needs for food, clothing, and shelter may not be met as the family environment declines through the illness. If they are fostered, they face economic and psychological insecurity that may never be alleviated. Land, home and possessions may be taken from them by relatives following their parents' death, leaving them homeless and without protection. In areas of Tanzania where AIDS mortality has been high, communities have taken measures to protect children, but in most cases, while local leaders recognized their plight, the community did little to assist them. Charitable individuals sometimes provided care. There are no social services responsible for their well-being or for providing assistance to the families which care for them.

The burden on the aged

While grandparents are responsible for the care of roughly half of all orphaned and fostered children in Tanzania, the burden of extra children to support can be severe. With no social security and few pension systems, most of the aged continue to farm to maintain a minimal standard of living. Despite poverty, most adhere to traditional cultural ideals of family care and will conscientiously assume care of their grandchildren, although this may mean considerable hardship:

Older women, reaching the time of life when they expect to rest, are having to find the strength to start over. In Morogoro town, one grandmother had to leave her country home to move to the city to care for the children her daughter left behind when she died of AIDS. Every day this elderly lady carries loads of rocks from the river behind her house to her front yard where she sits breaking them into smaller pieces. In three months she can break enough to fill a lorry. One load will earn her [\$24.00]. She says she will continue to do that for her two grandchildren until her body breaks down, even though her head pounds from the pounding of the rocks and her neck and shoulders ache from the effort (NAFCAA, Morogoro).

One elderly couple had taken in 6 grandchildren from two different daughters who died of AIDS. The family were all originally from the mountains and the grandfather had worked in the regional hospital for 22 years before retiring. They were living a fairly middle class existence before he took in his two unmarried daughters' children. It cost him a lot of money when his daughters got sick. They first went to hospital and then traditional healers. They and his wife (who looked after them) had to stay a long time with the traditional healer while he went looking for money to pay the healer. He and his wife had planned to retire to their *shamba* but instead he has had to find work as a night watchman to buy food for the children. He has not been able to afford school fees for all the children. The oldest has dropped out and sells peanuts. The second oldest boy is at the head of his class and sells peanuts on the weekends to get enough money. He is behind in his fees but not his studies. The grandfather is 71 years old. He earns enough money at his job to buy food for all the children. Should he die his oldest

son will take care of the children. He has a large family. The family is well respected in the neighborhood and has many family ties in town and in the mountains. Nevertheless, these days they are living in comparative poverty (NAFCAA, Morogoro).

The widow is a senior nursing assistant at the district hospital and has three surviving children, one of whom is married and the other two under care. She nursed her daughter, who had come to her from the city, for some months before she died of AIDS in September, 1993. The daughter left her with two young children, aged four and two-and-one-half. The younger child is frequently ill, probably an AIDS-related problem. She has difficulties feeding the children who dislike cassava meal and fish, the staple foods of the area. They prefer the more expensive maize meal, meat and beans they grew up on in the city. The children's father, who has AIDS and who has moved in with a traditional healer some distance away, has not communicated since his wife's funeral. Apart from an occasional remittance from her married daughter, the woman has to manage with what resources she can muster, which is basically her unenviable wages. She frequently has to absent herself from work in order to nurse the sick child. Because of such pressures, she has applied for early retirement so she can concentrate on nursing the ailing grandchild. She hopes to be able to get by with farming (NAFCAA, Mwanza).

Care for persons with AIDS

Across Tanzania, testing, counselling, hospital and home care are not widely available, and are provided almost exclusively by NGOs and groups of volunteers. In most areas, government workers were effective only if they were working closely with NGOs.

HIV testing

In all regions, HIV testing was non-existent or inaccessible. Test kits are available from the government only for the blood supply, and in areas where donors have sponsored serological research. Health-care providers are inhibited in assisting patients because they do not want to diagnose HIV without positive confirmation, and patients are often discharged without diagnosis. Where testing is available, results are often delayed and patients do not return to get them. Physicians are not clear about what treatment to recommend or are rushed by heavy job responsibilities. Lack of a definite diagnosis and poor referral systems, as well as undying human hope, encourage patients to seek care at mission hospitals, and from traditional healers, some of whom are using efficacious, scientifically verified local preparations to relieve AIDS-related conditions, prolong life and improve its quality:

Many patients seek treatment from traditional healers particularly in rural areas. In Dodoma, at least, traditional healers are relatively benign, encouraging things like good eating habits and rest. The [government] keeps a registry of traditional healers and maintains good relations with them. Traditional healers apparently come to the hospital seeking patients. On the other hand, traditional healers can cost quite a bit of money demanding anything from [\$60.00] to many goats. They also serve to reinforce the idea that AIDS is linked to spiritual beliefs. One traditional healer in Dodoma town argued that illness is caused by various spirits and some spirits can be called forth to destroy others. He claims to be able to rid the body of the AIDS virus within 21 days for a fee of [\$8.00]. By the time most AIDS patients die they have completely exhausted the resources of their immediate and extended families (NAFCAA, Dodoma).

Home care

Health care providers are inhibited in the advice they can give to family care-givers by their inability to make a specific diagnosis without testing and lack of clear guidelines for home care. Some home care counsellors say that the family begins to reject their visits because they do not have equipment, supplies or other material assistance. A manual for families based on the idea of 'universal precautions' or generally sound hygiene and sanitation advice was not available at the time of the study, although AMREF finished a Kiswahili manual for home caregivers at the end of 1994. AIDS patients at home tend to be isolated by their families and from the community, in part because of their immobility and diminished ability to communicate. In some cases, too, families are too poor to purchase basic supplies for cleaning, making patient management very difficult. In any prolonged illness, including AIDS, fatigued caretakers lose patience because they have persistent, competing work demands. There are no hostels and only a few day centres for persons with AIDS to reduce their isolation, stigmatization, and loneliness, and increase community acceptance and awareness.

Counselling

Counselling is generally provided by NGOs or hospital personnel who volunteer after work hours, making dedicated, but emotionally draining, efforts to assist. Few are trained in social welfare and family dynamics. Most training is cursory, geared to pre-test and post-test counselling, and is not to advise people about living with AIDS. Physicians and nurses often have not discussed their division of labour, lines of authority, or responsibilities for counselling, and avoid it because their workloads are heavy and they are not trained. Where counselling and assistance for home care is available, it increases family and community acceptance of persons with AIDS and their survivors. Counsellors assist patients to plan for their children's future and to extend their quality of life with proper care and nutrition. Without counselling, many hospital patients feel they are being told to go home and die, and their survival chances are reduced.

Assistance for orphans

By law, government Social Welfare Officers are responsible for licensing and supervision of orphanage conditions and admission; counselling families and parents on care and support of children; assisting applicants for adoption; counselling parents and children about behaviour problems; probation; prevention of child abuse; and tracing relatives of children in orphanages. These responsibilities give them considerable authority, although their Ministry is very poorly resourced and they are generally the last step before court. Their traditional role in AIDS-related matters is quite small, and lack of new definitions has created friction between Social Welfare Officers (Ministry of Labour) and AIDS Control Co-ordinators (Ministry of Health). If a new role in assisting families with AIDS were defined, Social Welfare Officers could work with RACCs and DACCs and be more effectively involved, but many officers would need additional training.

Tanzanians define an orphan as a child who has lost both parents. Maternal orphans generally suffer more than paternal orphans because men are not practised in child care or housekeeping, and generally do not show children much affection. In the event of remarriage, stepmothers frequently mistreat children, with or without their father's knowledge. Orphans under the care of step-parents or paternal relatives other than grandparents fare much worse than those under the care of grandparents or maternal aunts. Fostering prospects for children born of single mothers, especially if they live in town, are bleak. Most orphans are children of relatively young parents who die before they are able to establish themselves by acquiring significant assets, especially real estate, to bequeath to their children. Orphans with AIDS fall sick frequently, creating additional expenses for their foster-parents. Many caregivers are themselves entangled in struggles and animosities between the maternal and paternal sides of the family, and male relatives frequently bend traditional inheritance rules to suit selfish motives and disinherit their brother's widow and children.

Families are accepting persons with AIDS, and will not refuse orphans because they do not want to lose face with their families. Girls are easier to place because of their domestic labour potential, which partly accounts for the preponderance of male street children. Both male and female children are expected to help with all facets of household work, and are also expected to work in place of or in addition to schooling. The general poverty means most families struggle to survive, and cannot provide easily for additional children. Orphans may suffer malnutrition and lack of health care, or be deliberately neglected or abused from greed or as economic pressures build up:

In Dodoma relatives have taken children in, squandered their inheritance and kicked the children out of the house to fend for themselves. In Kilombero, Morogoro a young girl is left alone to care for her younger siblings. The only way she can earn any money is through cooking *pombe*, the occupation which her mother, now dead of AIDS, had formerly engaged in. The village leadership fear that this girl will suffer the same fate as her mother. Near Iringa town a 13-year-old boy, his 15-year-old sister and their two younger siblings have been living alone since the death of their father in February. Their mother had died two years previously. Their father's last wish to his son was that the children should stay together and not quarrel with each other. He left them no money and no food. No relatives have come to care for them although they know of the father's death. An elderly neighbor, a woman, gives them some food when she can. Some days they don't eat. The 15-year-old sister has begun to disappear for periods of time; when her brother asks her where she has been she shouts at him.

Double orphans often have great difficulty. One boy had good attendance and was doing well in school. First his mother got sick for a long time and then died. Then his father got sick. During the time his father was sick the boy's material condition declined. He continued to wear the same worn out uniform, he was dirty, couldn't pay his school fees and was hungry. His behavior also changed. He was unhappy, lonely, and ashamed. He and his three brothers were taken in by his sister who finished primary school in 1988. She has three children of her own and her husband is making very little money doing petty business. His attendance became erratic. School children often know when a classmate's parents have died of AIDS and they will tease them. Teachers notice many emotional changes in orphans who have often seen their parents die of AIDS. Many seem confused, some act as if retarded (NAFCAA, Dodoma, Iringa, Morogoro).

In most regions, the social norms for fostering relatives' children were strong, but the circle of responsible relatives is decreasing and the costs of raising children are increasing. Stigma associated with AIDS affected decisions to foster children, but the full impact was difficult to assess. The strong normative pressure to foster children may operate in the days after the death of the parent, but cannot continue when faced with the day-to-day realities of feeding, clothing, and caring for additional children. Children are universally viewed as *mzigo*, a burden or a load. Most children are taken in by relatives who genuinely care, love them, and try to do the best they can for them, but many people experience additional children as a burden. Few can afford to send their own children to school, or provide food for additional mouths. School teachers reported that the standards of living of orphaned children dropped drastically upon the death of their parent, and some come to school dirty, unfed, unable to pay their school contributions, embarrassed by their condition. Many have high absentee rates. Most are forced to engage in petty business, selling peanuts, ice cream, and cigarettes to support themselves. In some cases, after the parents' death, no one provides assistance:

Nasibu attends primary school in Iringa town. His mother died of AIDS in 1992 and his father died 4 months ago. Nasibu lives in the house his parents died in with his 15-year-old sister and two younger brothers. He has no money, no food in the house, and no plans for the future. No relatives have come to take them in. He comes to school because the teachers have so far been ignoring the fact that he

cannot pay his fees, and one teacher has agreed to look in on Nasibu to try to keep him from life on the streets (NAFCAA, Iringa).

Some foster-children suffer from lack of affection, exploitation of their labour, denial of food or other necessities of life, and lack of educational opportunities. Instances of extreme cruelty and physical assaults have also been documented. Some caretakers take on orphan-caring responsibilities in the expectation of material gain, inherited property, or the relief items donated by AIDS service organizations:

A next door neighbor who used to give food to the orphans soon burned out and now does not even visit them. A dear and trusted friend of the orphans' late father never turned up for the funeral and hasn't been seen since. He disappeared with his friend's bank book and a key for the family's post office box. A distant male relative who initially assumed responsibility for the orphans' welfare, especially by caring for the farm, soon started to behave like the owner. He would appropriate most of the produce, leaving the children with nothing to eat. He also took away some of the household items, ostensibly for safe custody. Village authorities banned him from visiting the orphans' home when they discovered his evil intentions (NAFCAA, Kagera).

Orphans are extremely mobile, fleeing bad memories and bad situations, looking for other relatives or economic opportunity. For this reason, street children's centres across Tanzania would like to start a co-operative network so relatives can be traced and placed. Without placement, children end up abused and neglected on the streets of major towns:

One ten year old boy fled Bukoba in fear two years previously after his parents had died of AIDS. His slightly older brother and he were living alone. His brother, also very young, was making money taking fish back and forth to Dar es Salaam. He had told his younger brother that his parents were killed by evil spirits that lived in their house. The evil spirits had been brought by Idi Amin and his brother had seen them. When his brother left to go to Dar, the boy was terrified to stay in the house alone so he followed his brother, sneaking and hiding the whole way. In Dar he ran away from his brother, not entirely intentionally. He wandered until finding the bus stand and snuck on one, and it deposited him in Iringa.

He stayed at the bus stand until he was given a job 'calling' the passengers to the bus. He spent his life on the Kwacha Video Coach. The bus leaves Iringa at 10:00 AM and arrives in Mbeya at 4:00 PM. It departs almost immediately for Kiera arriving at 8:00 PM and leaves again to return to Iringa the next morning at 4:00 AM. Eliasi was responsible for calling the passengers to the bus at every stop and assisting them with their luggage. Passengers like young, amusing children and Eliasi's job was to get them to choose the Kwacha Video Coach. Eliasi seldom had enough food to eat or clothes to wear. He spent nearly two years living on the bus. He was constantly in motion and constantly working. When he was taken in he was malnourished and afflicted by various parasites.

The boy's story, while unique, mirrors the experiences of other boys who have no one to care for them and take to the road. Some are searching for relatives to care for them. In Ilula, Iringa orphaned children often start hanging out in the local hotels looking for small jobs to earn food. Then one day, village leaders say, they just disappear. Most of the boys in the street children's centers are from diverse regions. They travel very far in search of a home. Hopefully, intervention strategies will prevent increases in street children but street children's centers need to be supported to help those children who fall through the cracks.

Some who come to the street children's center have lost their parents to AIDS and have been neglected by their guardians. Boys most often show up on the street; girls are taken in to be house girls or trade sex for a place to sleep. It is difficult to get detailed family histories from the children but some 200 children may be moving in and out of street life. The center has 34 boys; approximately 20 of these report that their parents are 'divorced'; 9 report that they are orphaned; 17 boys report that they do not know where their fathers are, almost all the others report their fathers as at distant places like Dar es Salaam and Arusha. Two of the boys have been identified as AIDS orphans. Others may be but the information is difficult to obtain. Many of the boys have travelled around the country a good bit (NAFCAA, Iringa).

In the past, orphanages served children under the age of three whose mothers had died in childbirth. The children were placed as quickly as possible with the father or other family members when they were old enough to feed themselves, although the physically or mentally handicapped may have remained in orphanages for most of their childhood. The Children's Home Act Number 4 of 1968 specifies that a child under 18 years of age can remain in an orphanage if necessary, or if physically or mentally handicapped. However, institutions were strongly advised to return children to their families or relatives between the ages of two and three because children adapt better if they are taken into a family while they are still young. Some orphanages are working to make the integration of the child into the Tanzanian community smoother by encouraging visits and interaction.

Most Tanzanians do not regard institutionalization as desirable, but in the absence of institutional care, direct assistance, recommended in many previous studies and programs, may be necessary to help a family during the most difficult periods of shortage. The greatest difficulties are experienced by single or widowed mothers, who have difficulty not only in providing for children economically, but also in controlling older children emotionally and psychologically.

Tanzania's legal guidelines for formal adoption require that a potential parent must apply to the court for permission to adopt, and parents or guardians who give a child up for adoption must agree to do so before the court. In any adoption proceeding, the court appoints a guardian *ad litem* who investigates the situation on behalf of the court to ensure that there are no living parents or relatives who want the child, and if the conditions of the adoption are in the child's best interest. This investigation is usually conducted by the Social Welfare Officer within two weeks to a month. Traditionally, formal adoption by a relative was not actually necessary, and if a relative took the steps to formally adopt a child, his or her motives were viewed suspiciously. Now, however, the Social Welfare Division feels it is important to use formal adoption mechanisms so the rights and responsibilities of adoptive parents and children are made explicit. Despite clear definition in Tanzanian law, legal adoption procedures are not widely known, perhaps because they are not often used:

[most people believe that] children cannot be given up for adoption if any relatives remain alive. Couples [are] waiting to adopt but...unable to find any children without relatives...[In one town], a neighbor was interested in adopting one of the toddlers [in an orphanage]. It could not be done because the father had stated he would come for her one day. He had not been seen again since leaving the child with Social Welfare...there should be a way relatives can legally renounce claims to children they don't want so others may take them in (NAFCAA, *Morogoro Report*).

The 1993 Government of Tanzania *National Programme of Action (NPA) to Achieve the Goals for Tanzanian Children in the 1990's* advocated a community-based, integrated planning approach to promote the welfare of women and children, including orphans. The Social Welfare Division drafted guidelines in 1993 for children who are orphans, handicapped and mentally disabled, destitute, or traumatized by disasters, and street and working children, but these have not yet been adopted. They propose to address the problems of orphans through careful situation analysis and monitoring; assisting

caregivers to develop income-generating skills; promoting foster care and family adoption; vocational training, tools and assistance with resettlement.

Community responses

NAFCAA found that community responses to the problems of AIDS were not common for many reasons, among them poverty and the competing concerns of survival; AIDS is not perceived as any more serious than other common fatal illness until mortality in a community is very high; AIDS is viewed as an urban disease which will not take a foothold in rural areas. Most rural AIDS cases are persons who returned to their homes after contracting the disease in the city. Local leadership has diminished.

Villagers are well informed about the signs and symptoms of AIDS, but are slow in labelling people until there are a series of severe bouts with identifying illnesses.

In 1990-91 there were several AIDS cases returning to the Kondoa area at the same time. People became frightened. They associate the disease with witchcraft even though they know how it is spread. They have become very suspicious of outsiders. Grain and vegetables are sold only to traders from Kondoa and although the area is known for sewing *kofia*, and thus a potential business center, residents will only sell them to a few known traders. Residents are afraid of those returning from travelling in other areas. Men and, especially, women find it difficult to marry if they have returned from living in towns. In general only a few young men now travel; most stay and farm. Women continue to travel but many don't return. Parents look after returned AIDS patients but they are very cautious in the amount of resources expended on their care. When one who has travelled becomes sick and claims to have TB or malaria they demand to see their health certificate to see if the doctor has recorded HIV before taking them to the hospital. Otherwise, the fact that a person has HIV is deeply hidden. For this reason, it was extremely difficult to get people to admit to any problems (NAFCAA, Dodoma).

There was a fair amount of complaining from village elders that those who were dying were the wealthiest ones in the village, and people just took the children in to get the wealth left to them. When they had used it up they kicked them out. Those dying may have made plans and made their wishes known, but these were not followed after their death. In most cases such plans are made very quickly because few patients admit their disease until the very end. The safeguarding of an orphan's inheritance is entrusted to family members, and some are not trustworthy. The death of a 'businessman' often results in a great deal of dispute over the property and children. Village elders are not pleased with the behavior of fellow villagers (NAFCAA, Iringa).

Ward and village government leaders and teachers are often concerned, caring individuals, impressive in their knowledge of local problems, genuinely upset when they feel people are behaving improperly, but unsure of their jurisdiction in these matters. With some direction from the government, elders, leaders, and teachers in some regions have spoken out and condemned such practices. In Kagera, two districts have taken advantage of a provision in the law which allows them to adopt local laws protecting widows and orphans. In the process, they restored some of the moral balance to an Iringa community:

Residents of one community have a 'council' which ensures that the right person inherits the property of his or her deceased relative. A similar thing is done for an orphan. However, for young orphans the council entrusts the property to an adult relative and guardian who has to hand over the property to the orphan once he or she is over 18. The elders did not think that religious beliefs and actions affect the

care of orphans. The advantage of taking care of an orphan only comes when the latter is mature, has good character and remembers to help you as his or her care giver. They also admit that it is a great burden to take care of an orphan, especially because of the expense of medicine and education (NAFCAA, Iringa).

Most villagers were not willing to stigmatize families with AIDS, to ignore children who need assistance, or to condone families who leave widows and their children destitute following the death of a husband. Some villages had plans for day care or for income generating schemes. In most cases, workers from the Ministry of Community Development, Women's and Children's Affairs were not functioning because of confusion about political party viability and relationships. Responses by religious groups were most common. Health workers were disappointed and surprised by the lack of community support for their work. However, they are better informed and can understand the long-term effect of the disease and its implications better.

Despite the lack of community response, there are people of goodwill everywhere who want to be mobilized. Teachers often contribute to maintain children in school, take them to the dispensary for health care, ensure they have enough to eat, and provide assistance or shelter to abandoned children. Teachers and village government leaders were often well-informed and conscientious individuals, had a sympathetic understanding of the circumstances of single mothers, understood that nearly anyone can get AIDS, and realized that children should not be made victims of AIDS stigma. Burdens could be lightened by solving these problems at local levels without outside financial assistance, but the schools handle the issues in different ways and need to be apprised of the procedures for waiving national and locally assessed school fees for orphans. First national policy and law needs to be clarified, and local leadership may need encouragement to champion the needs of AIDS victims.

In cities, reactions may be harsher. Persons who are thought to have AIDS have been evicted by landlords who feared stigma would lower property values. Some employers are screening employees on the basis of symptoms and firing them to avoid long-term medical expenses. The worst affected are the self-employed because they lose their ability to work and have no source of social assistance to fall back on. Urban residence often makes it harder for a family to cope because supportive family members may not be close by. There is greater nucleation of families, and people are not as well known to their neighbours and communities. There also may be rapid shifts in settlement in market towns.

Tanzania's agricultural estate communities are a special case. Companies which employ 5,000 or 6,000 individuals may have total community populations of 30,000. Law and custom have interacted to ensure that housing, sanitation, and health care are good for workers and their dependants, but do not guarantee company concern with the surrounding community. However, official company communities and their surrounding service communities cannot be separated in realistic AIDS prevention and care programs because they continuously interact. The populations of the surrounding service communities are not only large but ethnically and economically diverse. Retired workers often settle down on very small plots, and workers making a relatively good salary may have multiple wives, families, and girlfriends for whom they provide housing after installing their one permitted family in company-assigned housing. These employees have migrated within Tanzania, may not maintain significant ties with their home region, and cannot rely on their extended family for help.

Immigrants from all over Tanzania also come to these areas to engage in petty business. At most estates, seasonal labourers arrive by the thousands. For a period of time they make relatively good money. Petty business men hope to sell them consumer commodities. Petty businesswomen hope to sell local beer, food, and sexual services. Even women from distant villages may bring their produce to sell on designated market days and stay to earn a little extra money or gifts in exchange for sex. Village leaders in these areas report many people dying from AIDS and many orphans living on their own. Private companies provide no support for surrounding communities, except for occasionally hiring day labour. Government owned parastatals may provide basic medical care for local communities but hospital staff are instructed to give better care to employees. In addition, parastatals in Tanzania are rapidly being privatized, and agreements to share company facilities may be overturned.

Most temporary workers will have returned home before they exhibit symptoms. If they become sick on the job, they are dismissed and sent home. They will not be hired back. Permanent employees are also dismissed and sent home, after they have exhausted the six months of sick leave required under Tanzanian law. Those who choose to may be permitted to remain in the company hospital until well enough to be discharged or until death. Their wives and children will also be given money to return to their home region. Older daughters and sons of employees are common victims of AIDS. They will be cared for in company hospitals.

Residence and ethnicity

NAFCAA found that the most important determinant of a family's response to AIDS is its economic condition. An AIDS illness diminishes family resources through reduced earnings, and increased expenses for hospital care, drugs, or traditional healers. By the time a person dies, in many cases, there are no resources left for the survivors. Support from family members and friends may be more available during the early phases of illness, but are exhausted by the illness and funeral and unavailable to meet the needs of surviving children. Orphans garner much less support from neighbours and kin. Thus, more direct material support may be required for orphaned children than for AIDS patients. Many personal factors also have a strong effect on the situation of persons with AIDS and their families. People who have good relationships with their relatives, friends or workmates will receive help more readily, which is true of any crisis. Gender also makes a difference. Men with the disease will generally receive loyal care from their mothers and sisters, while women may be abandoned by their husbands when they are ill with AIDS.

Across the country, there are traditional forms of interfamilial assistance in the event of sickness and death which are still important, including shared labour for agriculture and assistance with household chores on a temporary basis. There are mutual assistance organizations, to lend or give money for members' hospital and funeral expenses or to assist at weddings or with other enterprises. These are not segregated by gender except among Muslims.

There is little ethnic variation in family and community response to persons with AIDS or orphans, but ethnicity does determine rules of property inheritance and the treatment of widows in many cases. In groups where women can own property, their welfare following the death of their husbands is more secure. In areas with high bride price, the husband's relatives feel entitled to recover their property. Muslim communities were the most organized because the Koran is specific about inheritance and about protecting orphans. Women can inherit property, although their share is very small. Community leaders also have the responsibility to follow up and ensure that inheritance rules are followed by the family.

Government role

Government personnel at all levels operated with many constraints, including lack of materials, supplies, time, fuel, and vehicles. Government resources are available and personnel are in place and functioning in some regions, but in others they are not. There was also great variation in individual effectiveness depending on individual drive, commitment and leadership. Some government personnel were doing well because they had both a clear vision of their role and a strong commitment to creative approaches to problem solving, including developing public contributions for programs.

The public did not have much confidence in the ability or willingness of central government personnel to help. Antagonism is due, in part, to the central government's lack of resources and tangible signs of ability to assist. In other cases, the traditional roles of government personnel have been antagonistic to individuals:

The crisis of confidence in relation to the role of government in social service-related activities is so serious that it would be ill-advised to channel resources for orphan support through the government. Families invariably rejected direct involvement of government in their support. Their perception of

government, rightly or wrongly, is one of an institution which has little sympathy for their problems and where some of the resources meant for their support would line the pockets of private functionaries. The objective reality may be different from the above perception, but these sentiments cannot be ignored in formulating an assistance policy (NAFCAA, Mwanza).

However, they played an important role in some areas by reforming local inheritance laws in order to protect the property rights of widows and orphans. In a rapidly changing economic and social environment, traditional law relating to inheritance, which was premised on trust, is frequently distorted to benefit the powerful and aggressive and to disadvantage the socially disempowered: the women and children.

In most cases, village and ward level leaders are trusted and still respected, and may be successfully involved with stimulating community responses to AIDS. Local government personnel were committed and hard-working, although there was great variation in the roles played by regional and district personnel. This was due, in many cases, to the fact that government personnel are not clear about their roles in relation to persons with AIDS or to orphans, so they develop roles according to their inclinations, backgrounds and relationships with other officials:

The virtual paralysis of government AIDS control activities is positively damaging. Since government is an important agency of social change and it has a well-established system of reaching the public, it is important that its resources be increased...to advance the cause of AIDS control. Such interventions ...should target specific, identified gaps in order to avoid resources going to fund general administrative expenses. Actual implementation of what is recommended will be done by NGOs and community-based bodies under the general supervision of government.

Lack of guidelines for roles or training to develop new roles in areas of overlapping responsibility has led to confusion and contention in some areas between Regional and District AIDS Control Coordinators (RACCs and DACCs) and Regional Welfare Officers (RWO). One example is in establishing responsibility for orphans of AIDS. Regional Welfare Officers have overall responsibility for the welfare of children requiring institutional support. AIDS Control Co-ordinators, on the other hand, have no mandate to care for orphans. However, because of their position (usually associated with regional and district hospitals) and knowledge of NGO programs, they are frequently informed of cases of AIDS patients whose children will be left in difficult circumstances. Some effort has been made to promote collaborative relationships, including delineation of roles and responsibilities by Ministry personnel; workshops and regular meetings to raise awareness; and joint plans in regions and districts, but the effect is limited to date.

There were no clear guidelines and standards for non-government organizations, or machinery to monitor activities. Government response to NGO operations has been of two kinds. The most effective government personnel had aligned themselves with an NGO which resources them so they are better able to execute their responsibilities. In the negative cases, the fact that these organizations have resources that government workers lack has generated bad feelings and jealousy. One organization claimed that a government official had blocked its NGO registration for this reason. In general, the infusion of new resources into a community can have this effect, not only between government and non-government personnel, but also between branches of government, who receive variable support. Most actual work for families affected by AIDS is done by NGOs, but government personnel have an important co-ordinating role to play and can stimulate collaboration by adopting a positive attitude:

Some problems are by no means unique to Tanzania, [including the difficulties inherent in] coordinating and interacting with other branches of government and NGO's. The specific problem began when the sisters at the town orphanage expressed concern over the number of babies that were dying of AIDS and their worries about caring for the children. Social Welfare offered to test the children so the sisters would know which children might need special care and contacted the regional

hospital which agreed to do the testing. When the RACC heard about it, he became very upset and demanded to know on whose authority the tests were ordered. This jurisdictional dispute was actually solved in a way which brought further problems. The founder of an NGO which provides AIDS counselling services volunteered to go to the orphanage and conduct some seminars to inform the sisters and show them how to safely care for babies in the final stages of the disease. The end result was that everyone involved felt others were trying to control the situation.

These jurisdictional arguments have persisted. The NGO director had begun to do home counselling but was told by the RMO and the RACC that she should not because that is what they wanted to do. She says they refuse to refer hospital patients to her, but she has organized her own system whereby she holds day long seminars for ten-cell leaders in how to recognize problems and what to do about them and encouraging them to send people to her. Meanwhile her solution to the hostility is to pay the RACC and Urban DACC per diems to accompany her on the many prevention seminars she gives in town (NAFCAA, Morogoro).

Conclusions

NAFCAA findings were similar to those reported in earlier studies of families affected by AIDS. Problems of families with AIDS are problems of poverty, and AIDS exacerbates existing family stresses. AIDS sufferers seek the assistance of a wide variety of healers, including traditional, and often exhaust family resources in the process. There is little or no institutional care available for persons with AIDS, and most care is provided at home. Women are responsible for most of the home and hospital care of persons with AIDS. Children suffer physically, economically and psychologically. Community based care is preferred to institutional care for orphans, and social norms prevail that dictate that children are absorbed by family at various degrees of relationship, their success related to the amount of resources available. Changes in family structure had already been occurring in Tanzania before the AIDS epidemic. Large proportions of women are self-supporting, and large proportions of children are fostered. Health and nutritional status is low, and the distribution of AIDS seems to follow patterns of deprivation and household organization. Problems in cities are greater than those in rural areas for persons with AIDS and for their survivors. Problems of deprivation after a death followed patterns of deprivation leading to infection in the first place.

Some of the findings of the study are new for Tanzania and for studies of this nature, which NAFCAA identified simply because of its wider geographical scope. First, the status and care of children in Tanzania is different from that portrayed in earlier studies. Relatively large proportions of children are fostered compared to other African countries, so that a high proportion of children in Tanzania may live some portion of their lives without the protection of a parent, even before increased AIDS mortality. The proportion of children orphaned is higher than expected from earlier census based estimates and exceeds NACP estimates widely. The proportion of households headed by single women is also high compared to other countries in Sub-Saharan Africa.

The study determined that, in Tanzania, variation in care and treatment of persons with AIDS and their survivors has less to do with ethnicity than with economics, and that the availability or access to resources makes a deciding difference for most families in the quality of care provided. The determination that there is a great deal of similarity throughout the country in the problems of and approaches to caregiving may not be true for countries with a larger resource base, but in Tanzania, the ceiling of variation may be low because poverty is so widespread. It seemed that more children, widows, and elderly guardians were falling between the cracks than reported in other studies, perhaps because poverty is more widespread.

Donor emphasis on NGO funding has substantially shifted government workers' roles and disempowered them at all levels. Since government workers had no choice, the smart ones aligned

themselves with NGOs to get resources. Central government could improve the situation of families with AIDS by co-ordinating ministerial interactions and defining roles more clearly. In addition, scarce resources could be more wisely employed. The report recommends that social workers be incorporated into the country's counselling scheme so the entire social welfare system is involved on a case-based system of care. Heretofore, availability of WHO funds for counselling encouraged health workers to monopolize counselling although their social-worker colleagues were better trained for the job. WHO's emphasis on pre-test and post-test counselling left most people who counsel unprepared to counsel families with AIDS.

Communities are not mobilized in the general way that professionals might wish for or stubbornly insist on, but concerned individuals are trying to help. Local people could be motivated to protect widows and children by being informed of initiatives in other parts of the country. Some simple things help a great deal — revolving credit funds, infrastructural improvements in health and education, income-generating projects, vocational training, energy-saving projects for women — but these may not be sufficiently dramatic for public or private fund raising.

Follow-up activities

The Tanzania AIDS Project distributed the *Executive Summary of the National Assessment of Families and Children Affected by AIDS* to all Ministries, provided a summary to regional and district government representatives, donors and NGOs with programming interests in these areas, and held a national conference which included findings of other research studies in Tanzania. It is preparing a brief, popular version of the findings for translation into Kiswahili for distribution to interested organizations and individuals in the regions, and developing strategies to publicize findings to government decision makers and the general public so they are more aware of the magnitude of the problems AIDS creates.

The Project may assist AMREF to distribute its manual on home care, and support mass popular education in care and counselling as well as prevention using newspapers, radio, television, and folk media. Campaigns are conducted in Kiswahili, by partner NGOs in co-operation with religious organizations, political parties, and civic groups. TAP is working with the Division of Social Welfare to develop Ministry training programs to examine and update the role of Social Welfare Officers in assisting families affected by AIDS. It has encouraged and supported regional and district planning and strategy development sessions with R/DACCs, R/DSWOs, and NGO representatives, and requires AIDS Project field co-ordinators and NGOs with AIDS Project subcontracts to co-ordinate with government personnel in program development and encourage their participation through consultations and meetings. The Project encourages and supports NGO field trips and exchanges between regions, particularly with personnel in the Kagera Region, where program development is the most advanced.

The Tanzania AIDS Project is encouraging NGOs with resources for orphan support to target communities rather than individual households because there is a breakdown in service delivery systems below the community level, and family-level support has high manpower requirements and transport costs, and presents problems relating to monitoring and determination of eligibility. Forms of intervention to build the basic resource base of communities and strengthen their service delivery capacities are encouraged. Community and household approaches need not be mutually exclusive. One obvious virtue of the community approach is that, other things being equal, it would lay a foundation for long term self-sustainability of communities. However, shorter term assistance may be critical.

But field experience has revealed so much want, so many crises of human survival on a day-to-day basis, that the mundane issues of day-to-day existence for individuals and households can only be ignored at heavy cost to humanity. The starving widows and orphans, the families evicted for rent default or the children sent out of school for non-payment of school fees cannot wait for community projects, which cost much money, have a long gestation period, and are likely to be fraught with

managerial complications. It is therefore recommended that the approach to orphan assistance be double-pronged, targeting communities as well as affected families. At the level of families, support should benefit whole households rather than single out the orphans...Informants generally agree that if caregivers were to receive general support meant to boost their household economies, they would willingly and responsibly perform their caregiving function (NAFCAA, Morogoro).

The AIDS Project will encourage communities to help individual families by facilitating education, including reassessing their expectations for fees from all children; simplifying procedures for orphans to receive waivers of school fees and reducing the embarrassment children experience in doing so; and requesting NGO assistance in projects which reduce the overall need for fees, such as repair and construction of classrooms, and provision of furniture and study materials. AIDS Project NGOs are encouraging community philanthropy in larger cities and towns, both in donations to assist families and children affected by AIDS and to develop facilities or provide materials for assistance. They are supporting development of programs for street children in smaller urban areas served by Tanzania AIDS Project clusters and development of a national street children's network.

The Project is supporting revision of laws or other legal programming and education to protect the inheritance of widows and children orphaned by AIDS; supporting the creation of local 'legal defence funds' which women can use to defend themselves against claims on their property; and publicizing the condition of widows and children by distributing the film *Neria* nationally and using other media to stimulate public discussion of women's and children's rights, inheritance, and family responsibility under traditional law. AIDS Project NGOs are also encouraging local businesses to support programs to assist their communities in providing care and counselling. In the coming months, 1994 data on AIDS issues and orphaning will become available from the DHS, allowing review of findings on family structure by region to determine changes in household composition and growth in the orphan population. The Project will also support additional research on variation in family structures and orphaning practices by region, including a pilot study by NGOs in collaboration with the NACP of AIDS case and orphan data.

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