

# **Social Security Transfers, Poverty and Chronic Illness in the Eastern Cape:**

**An investigation of the relationship between social security grants, the alleviation of rural poverty and chronic illnesses (including those associated with HIV/AIDS) -  
A case-study of Mount Frere in the Eastern Cape**

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# Chapter 1 Introduction

The Department of Health estimations of the HIV/AIDS pandemic in South Africa suggests that 4.8 million inhabitants were infected by HIV by the end of 2000 (National HIV and Syphilis Sero-Prevalence Survey of women attending Public Antenatal Clinics in South Africa, 2000). The number of children orphaned by AIDS related deaths is anticipated to reach nearly 2 million by 2010 (Heard - University of Natal, "HIV/AIDS Statistics" 2002) . Both these statistics suggest catastrophic social consequences to family and community structures with the debilitation of income earners and the rise of child-headed households.

This research study intends to fill a gap on one aspect of the impending social crisis caused by HIV/AIDS. That is the lack of information on rural households access to and decision-making on household income as derived from state transfers (social security grants) in the context of wide-ranging poverty associated with chronic illness (including HIV/AIDS) and malnutrition. The study attempts an assessment of the role of social security grants in the alleviation of poverty and symptoms of poverty such as poor health and educational status in rural poor households.

## Study Objectives

This research study is concerned with the relationship between social security grants and the effects of malnutrition and chronic illness, including those associated with HIV/AIDS, on rural poor households ability to sustain an income to meet their basic needs.

The key objective is to assess the potential role for social security in alleviating poverty in households with an HIV/AIDS status household member and propose alternative public policy interventions for consideration by the Department of Social Development.

Given the centrality of social security grants to sustaining the livelihoods of poor rural households the study is contoured around households experience of income through receipt (or failure in receipt) of social security grants.

The study is concerned with household illness and death (including those associated with HIV/AIDS) and its impact on educational status, household distribution of income resources, food intake and health. This study thus centrally poses questions relevant to HIV/AIDS and income through receipt of state transfers.

In fulfilling the study objectives there is the need to distinguish between the medical condition of HIV/AIDS and loss of ability or functioning as a consequence of an HIV/AIDS related condition.

This study addresses the latter – in other words it is a study of the consequences for social policy of disability as a consequence of HIV/AIDS and not the medical condition of HIV/AIDS. There was, therefore, no detailed medical examination of households undertaken to determine their HIV/AIDS status.

This approach follows the original terms of reference of this research which is to investigate:

"3.1. what are the income and expenditure dynamics of households in poverty who have a household member with an HIV/AIDS condition ? What have these income and expenditure dynamics meant for the nutritional and educational status on non-infected household members, particularly school going children ?

3.2. Could government-supported social security interventions replace the income and other resources lost by the debilitation of a family member through HIV/AIDS ? Could such interventions support the family through the crisis period by building the capability of caring.."

The research is aimed at providing an in-depth understanding of social security grants and their relationship to households who are coping with lost functionality of economically active household members as a consequence of chronic illness and death (including those associated with HIV/AIDS).

The interviews are conducted in a unique, innovative manner which combines qualitative and quantitative methods. The results provide important insights into what the financial consequences of chronic illness (including those associated with HIV/AIDS) and malnutrition. This is the basis on which further detailed research may be pursued.

### **Building on previous public health related research in Mount Frere**

This study builds on the foundations of a number of pioneering public health related initiatives led by the Health Systems Trust and the UWC School of Public Health in Mount Frere as a response to the national Department of Health's Integrated Nutrition Programme (INP) policy. The INP not only seeks to improve the quality of services but is also a part of a comprehensive strategy to address the underlying socio-economic, environmental, educational and health related causes of undernutrition. This has required nutrition and health workers to develop a new understanding of nutrition which includes a change away from solely food-based and health facility located interventions towards community based operations and increased intersectoral collaboration. ISDS (Initiative for Sub-District Support), a project of the Health Systems Trust, has been facilitating the implementation of Primary Health Care policy in a number of districts. Since early 1998, UWC's School of Public Health has been actively engaged in the implementation of an INP in Mt. Frere district in the Eastern Cape as part of a sub-contract concluded with the HST.

## Chapter 2 AIDS, Poverty and Malnutrition

### Introduction

The discussion of HIV/AIDS on the African continent no longer revolves simply around issues of health. It has evolved, rather, into a deliberation of economics, national development and poverty relief. The study of how this particular disease affects individuals, households and the national economy reveals a complex but important relationship between HIV and poverty. In Sub-Saharan Africa, the rates of infection are actually higher among the wealthy than among the poor, but because the poor population is so much larger, infection among the poor is considerably higher in numerical terms. Economic growth, moreover, typically leads to higher rates of HIV in the poor population with large project investments resulting in labour migrations and family disruptions.<sup>1</sup> According to R. Bonnel, the growth effects on the greater economy are more pronounced the longer HIV has been around while HIV is most advanced in the weakest economies least able to adjust expenditures and revenues. School attendance rates decline, medical costs rise, economic opportunities for women become more limited, and infrastructural investment declines.<sup>2</sup>

Sound fiscal policies are eroding while gains in employment and economic growth are reversing in what Bonnel terms a “vicious cycle of underdevelopment.”<sup>3</sup> Martha Ainsworth of the World Bank, in her study of the impact of household death on the health of children in Kagera, Tanzania, notes that AIDS is slowly reversing a thirty year trend (1960-90) of improvement in the health and education of poor children, severely compromising their prospects for future productivity. Maternal infection rates for newborns in Southern Africa are as high as 30-40%. Children born with HIV suffer stunting, nutritional wasting, acute, chronic and persistent diarrhoea, failure to thrive, pneumonia, thrush, and neurological abnormalities.<sup>4</sup> In addition to this grim clinical picture, children infected with AIDS, if cared for by their family, are typically raised in household economically compromised by previous HIV infection.

According to UNAIDS and the World Health Organization, 90% of the 600,000 children under the age of fourteen who became HIV-infected in the year 2000 were born to HIV-infected mothers. Nearly 90% of these new infections were in Sub-Saharan Africa, while 70% of the global total of HIV-infected persons reside in Sub-Saharan Africa. The number of AIDS orphans (a child under fifteen years of age who lost one or both parents to AIDS) in South Africa alone is estimated to reach one million by the year 2005. By the year 2010, the estimate is closer to 2.5 million with the majority of these being under four years of age. Despite this, very little research has been devoted to the impact of AIDS at the household level in South Africa. Reflecting this lack of research, the authors of the Kaiser Foundation Lovelife publication, a report specifically devoted to the HIV/AIDS epidemic in South Africa, cited the need to rely on anecdotal evidence and research from other countries.<sup>5</sup>

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<sup>1</sup> R. Bonnel, “HIV/AIDS and Economic Growth: A Global Perspective,” *South African Journal of Economics*, Vol. 68:5 (Dec 2000), p. 848.

<sup>2</sup> “HIV/AIDS and Economic Growth: A Global Perspective,” pages 824, 825, 848.

<sup>3</sup> *ibid* p. 848.

<sup>4</sup> Martha Ainsworth, Innocent Semali, “The Impact of Adult Deaths on Children’s Health in North-western Tanzania,” *World Bank Policy Research Working Paper* (2000), p. 5.

<sup>5</sup> “Impending Catastrophe Revisited: An update on the HIV/AIDS Epidemic in South Africa,” *Henry J. Kaiser Foundation, LoveLife* (2001), p. 4, 8, 10.

The consequences of AIDS deaths, though similar throughout the African countries, are unlike those from other diseases. By striking adults in their prime, at the peak of their productivity and earning capacity, this disease disables and kills those people on whom families rely for their very survival.<sup>6</sup> AIDS is also characterized by the likelihood of multiple deaths in a given household.<sup>7</sup> The high cost of transportation to medical facilities and funeral expenses at a time when household income is diminishing due to reduction in labour time puts the household at serious financial risk.<sup>8</sup> With multiple deaths, the family's ability to cope is additionally compromised by the potential for stigmatisation and the inability or refusal of extended family to lend support due to either this same stigmatisation or the financial burden of deaths within the family.

Given the many factors characteristic of HIV/AIDS death-- what Gladys Bindura Mutangadura labels a "major form of idiosyncratic shock affecting households"<sup>9</sup> -- the financial cost to a household is considered to be as much as 30% higher than deaths from other causes.<sup>10</sup> The role of public sector intervention at the household level is the subject of much debate. There is evidence that family support systems are weakening. The burden of multiple deaths from a highly stigmatised disease has either lessened the degree to which families and communities are willing to assist or, in some cases, brought such assistance to a halt. Public sector intervention may be required to meet the basic needs of household's whose ability to self-insure has been compromised by HIV/AIDS.<sup>11</sup>

The purpose of this literature review is to assess household studies performed in Zimbabwe, Zambia, Thailand, and Tanzania, as well as an array medical literature on the relationship between AIDS, poverty and malnutrition. Section 3.2, therefore, comprises a discussion of household surveys and the methods used by different researchers. Section 3.3 involves an analysis of the economic impact of AIDS deaths on the household and a discussion of vulnerability within the household. Section 3.4. will focus on coping mechanisms and strategies used by households in the event of adult death. Section 3.5 relies heavily on the medical literature to explore the link between HIV/AIDS, poverty and malnutrition, while Section 3.6. assesses the recommendations for targeting, mitigation, and government intervention.

## Household Survey

The HIV/AIDS researcher conducting a household survey must begin by defining the household unit. Martha Ainsworth defines the household as "a group of persons living and sharing meals together in the same dwelling for at least 3 of the past 12 months."<sup>12</sup> Foster *et al* also defines the household as those people who cook and eat food together but without a

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<sup>6</sup> M. Lundberg, M. Over, P. Mujinja, "Sources of Financial Assistance for Households Suffering an Adult Death in Kagera, Tanzania," *South African Journal of Economics*, vol. 68, no. 5 (Dec 2000), p. 948.

<sup>7</sup> Gladys Bindura Mutangadura, "Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development," Paper presented at the AIDS and Economics Symposium (2000), p.13.

<sup>8</sup> "Sources of Financial Assistance for Households Suffering an Adult Death in Kagera, Tanzania," p. 948.

<sup>9</sup> "Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development," p.30.

<sup>10</sup> "Impending Catastrophe Revisited: An update on the HIV/AIDS Epidemic in South Africa," p. 9.

<sup>11</sup> "Sources of Financial Assistance for Households Suffering an Adult Death in Kagera, Tanzania," pages 950-951.

<sup>12</sup> "The Impact of Adult Deaths on Children's Health in North-western Tanzania," p. 11.

specific time frame.<sup>13</sup> Foster defines the AIDS orphan as a “child aged 14 years or less whose mother and/or father has died.”<sup>14</sup> This definition is consistent among researchers.

Defining the AIDS-affected family is a more difficult prospect for this type of research. In a five-year retrospective study on risk factors for AIDS-affected families in Zambia, Nampanya-Serpell used structured interviews of a purposive sampling. Based on information obtained by NGO’s providing services in the urban sample or mission hospital data for the rural sample, this research team was able to select families likely to be suffering from a recent AIDS death. The working definition of an AIDS-affected family in this case was one in which one parent, both parents or the principle breadwinner had died of AIDS over the five year sampling period (January 1992-December 1995).<sup>15</sup>

Mutangadura also used a purposively selected sample for her study of the impact of adult female death on the Zimbabwean household. In this case, the conditions leading to death among females were self-reported with no confirmation from medical examinations or records. The leading causes of adult female death were determined to be child birth, TB/coughing, malaria, diarrhoea, high blood pressure, and meningitis (in order of prevalence). TB and diarrhoea are considered primary manifestations of AIDS. This data, in combination with fact that 33% of deceased females had lost a spouse prior to their death and 48% had lost a child, led Mutangadura to accept the implication that “the leading cause of death in adult female in this purposively selected sample was AIDS related.” Focus group discussions, pointing to the brief intervals between the death of the female and spouse (or sometimes the youngest child) also indicated that AIDS was the primary cause of premature adult female death in the study.<sup>16</sup>

Ainsworth, in order to avoid telescoping and recall bias, chose not to use retrospective reports for her study of the impact of adult death on children’s health in North-western Tanzania. Instead, she questioned all respondents on four primary AIDS symptoms: chronic diarrhoea, weight loss, chronic fever and skin rash. She accepted only reports of child illness on the day of interview. Over 25% of the children were ill, with fever and diarrhoea being the most frequent symptoms. No parent or caregiver reported AIDS as the cause of child illness. Ainsworth noted that this was not surprising given that AIDS presents itself as a series of common childhood illnesses. Interviewers also took measurements of height and weight for the children interviewed to aid in determining child health.<sup>17</sup> Community health indicators were measured through questionnaires. Nearly 50% of the children were determined to be living in communities with AIDS cited as the major cause of adult death with the adult death rate (15/1000) being three times higher than would be expected without AIDS present.<sup>18</sup>

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<sup>13</sup> G. Foster, R. Shakespeare, F. Chinemana, H. Jamckson, S. Gregson, C. Marange & S. Mashumba. “Orphan Prevalence and Extended Family Care in a Peri-urban Community in Zimbabwe,” p. 6.

<sup>14</sup> “Orphan Prevalence and Extended Family Care in a Peri-urban Community in Zimbabwe,” p. 5. Foster notes that this definition is consistent with the Shona cultural definition in Zimbabwe.

<sup>15</sup> Namposya Nampanya-Serpell. “Social and Economic Risk Factors for HIV/AIDS-Affected Families in Zambia,” Paper presented at the AIDS and Economics Symposium (2000), pages 5-6, 15.

<sup>16</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” p.15.

<sup>17</sup> “The Impact of Adult Deaths on Children’s Health in North-western Tanzania,” pages 12-13. Interviewers in the Zambian study also took measurements of children under five in AIDS-affected families in order to determine nutritional status. Measurements were limited weight for age indexing and mid-upper-arm circumference.

<sup>18</sup> “The Impact of Adult Deaths on Children’s Health in North-western Tanzania,” p. 17.

In order to determine the relationship between household wealth and impact of adult death on the health of surviving family members, Ainsworth also took measurements of household assets. These included coffee as a proxy for cash income (as a tree crop and the major cash crop of the area, it is considered an enduring asset), durable goods, and type of flooring as an indicator of wealth. Though coffee was grown by over 75% of the children's households, 48% of the children lived in households that reported zero durable goods.<sup>19</sup> Thus, the households with the fewest assets had no durable goods, no coffee and a dirt floor, and Ainsworth was able to determine that "the impact of adult mortality on reported morbidity is critically linked with the household's wealth."<sup>20</sup>

Mutangadura, in order to target nutritional supplement programs to needy children, also questioned the Zimbabwean households she surveyed on changes in consumption of specific commodities. Though she found decreased consumption of most commodities following adult female death in the household, she was not able to separate the cause of this change from the rising inflation in the country. Mutangadura also took information from teachers on the frequency of fainting in school and was able to determine, in the end, that food security was indeed poorer following adult female death.<sup>21</sup>

Kongsin and Watts, researching the economic impact of HIV morbidity on the household in rural Thailand, acknowledge the distressing nature of the interviews. In 30% of the cases, they had to return in order to complete the interview process because of the respondent's emotional duress.<sup>22</sup> Their research team used key informants within the community to identify households with chronically ill members. They focused on the presence of chronic illness or incidence of death within the one year prior to the interviews as opposed to the cause of illness or death. Since they limited their study to illness (or death) in adults aged 15-49, they reasoned that most illnesses within this age range would be AIDS-related.<sup>23</sup> Foster *et al* chose to focus on the cause of parental death in the Zimbabwe study. They used interviewers trained in the method of "verbal autopsy" in order to categorize deaths as Not AIDS, Possible AIDS, Probable AIDS, or Undetermined. They also relied on focus group discussions with the groups composed of caregivers, community members and teachers. Though only one family stated AIDS as the cause of death, Foster *et al* determined that 50% of the adult deaths since 1987 in their sample were due to AIDS with 32.2% due to probable or possible AIDS since 1979. Acknowledging that verbal autopsy may not be the most accurate way of obtaining information on AIDS-related symptoms, Foster *et al* justified this exploratory approach by the importance they placed on the determining AIDS as the cause of death.<sup>24</sup>

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<sup>19</sup> *ibid* . Dirt floors, while significant as a low measure of wealth, are also significant in the higher exposure to bacteria for young children living in these households.

<sup>20</sup> "The Impact of Adult Deaths on Children's Health in North-western Tanzania," p. 20.

<sup>21</sup> "Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development," p.17.

<sup>22</sup> Sukhontha Kongsin, Charlotte H. Watts, "Conducting a Household Survey of Economic Impact of Chronic HIV/AIDS Morbidity in Rural Thailand: Methodological Issues," Paper presented at the AIDS and Economics Symposium (2000), pages 1-2.

<sup>23</sup> "Conducting a Household Survey of Economic Impact of Chronic HIV/AIDS Morbidity in Rural Thailand: Methodological Issues," pages 10-12.

<sup>24</sup> "Orphan Prevalence and Extended Family Care in a Peri-urban Community in Zimbabwe," pages 6,8, 12.

## Impact and Vulnerability

Because HIV/AIDS is a sexually transmitted disease, all those who are sexually active are at risk for contracting the virus.<sup>25</sup> Women are particularly vulnerable to infection during unprotected intercourse as the rate of infection for women is two to four times greater than that of males.<sup>26</sup> Those carrying other sexually transmitted diseases also carry a considerably higher risk of infection during intercourse due to skin lesions and open sores that expedite the exchange of blood between partners. HIV is characterized by a potentially long period of latency (10-20 years) after sero-conversion but prior to the expression of opportunistic infections. During this period the infected person is asymptomatic. This is followed by a one to two year period of AIDS illness prior to death.<sup>27</sup> During both latency and active AIDS, those carrying the disease are at risk for spreading HIV to their partners, or in the case of pregnant women, to their newborn children. As blood supplies become safer around the world, the risk of contracting HIV from blood transfusions diminishes. Most infants (90%) who contract HIV/AIDS will get it from their mothers either in utero, during birth or from breastfeeding. Newborns of mothers with HIV/AIDS are therefore particularly vulnerable to infection but the vulnerability does not stop there. These babies are born to mothers who are sick or will be sick. They are born into households that have most likely experienced at least one prior death. Should their HIV status become known to the community, they are subject to stigmatisation, rejection, and abandonment. This section will focus on the physical, economic, educational and nutritional impact of HIV/AIDS morbidity and mortality on women, children and extended family caregivers. The focus will be on poor individuals and households because they are the most vulnerable to risk and are the most likely to be affected by HIV.<sup>28</sup>

In many African countries, women are economically more vulnerable than men prior to experiencing of the impact of HIV. In Zimbabwe, for instance, women work more labour intensive jobs, earn lower incomes, have less access to social security, and have fewer entitlements to ownership of savings and assets. As is true in South Africa, Zimbabwean women also lack sexual and reproductive autonomy. Not only are South African women subjected to economic maltreatment and violence within the home,<sup>29</sup> they, like the Zimbabwean women, are denied the right to protect themselves from disease. Neither abstinence, nor mutual fidelity, nor the use of condoms is within the control of the female partner.<sup>30</sup>

Some researchers contend that poor African women also run a greater risk of contraction than non poor women. According to Bonnel, “empowerment of women through greater economic independence is associated with a lower HIV prevalence rate.”<sup>31</sup> Women with bank accounts, jobs or businesses are less likely to become infected. Women with education are more likely to hold jobs and education is, indeed, associated with lower prevalence in some studies. As a

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<sup>25</sup> In countries where education and discussion have been effective, the primary risk factor is IV drug use, but that is not the case in South Africa.

<sup>26</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” p.2.

<sup>27</sup> Gerald J. Stine, *AIDS Update 2001*, (New Jersey: Prentice Hall, 2001), pages 183-184.

<sup>28</sup> “HIV/AIDS and Economic Growth: A Global Perspective,” pages 828, 832.

<sup>29</sup> “Impending Catastrophe Revisited: An update on the HIV/AIDS Epidemic in South Africa,” p. 10.

<sup>30</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” p.2.

<sup>31</sup> “HIV/AIDS and Economic Growth: A Global Perspective,” p. 832. See pages 17-18 for contrasting evidence of contraction prevalence among the poor versus the non poor.

key determinant of independence, education raises the cost of becoming infected and improves knowledge of the risks.<sup>32</sup>

The loss of the mother in the Zimbabwean household has profound social and economic consequences. As the key provider of food, clothing and utilities, the mother is considered the “gatekeeper” of household food security. Not only does she spend more time with the children, attending to their daily subsistence needs, she spends more of her individual labour and income on household consumption. Without the mother, the children are more likely to grow up inadequately prepared for life and with reduced potential for meaningful social contribution.<sup>33</sup>

Children living in AIDS-affected households are perhaps the most vulnerable to the many potential impacts of the disease. A parent with full-blown AIDS is likely to bring other infections into the family. Increased exposure to infections can lead to higher morbidity as well as a lower nutritional status among the children. A parent who is ill with opportunistic infections characteristic of AIDS is not only less able to contribute income, but also less able to care for a child’s daily needs. If one calculates child health as a function of three main inputs (nutrient intake, medical care, and adult time input), it is clearly the parent or caregiver’s task to transform these inputs efficiently. Ainsworth and Semali cite Dayton (1999) as finding a “positive relation between parents’ morbidity and low weight for height in children under 10 in the same sample of Tanzanian children” they used for their World Bank Study in 2000.<sup>34</sup>

Though death of an adult may have a transitory negative affect on household welfare, death of a parent is likely to be more permanent. In the event of parent death, a substitute caregiver is less likely to be able to respond to the children’s needs, less able to transform inputs efficiently, and less likely to consider the children critical to household welfare. Ainsworth and Semali found that adults in their study considered their own children to be a source of future income and security and thus had economic incentives to care for them. Orphaned children, on the other hand, were not considered old age security for those other than close relatives. Households taking in children who are not close relations therefore had no incentive to provide health care and schooling.<sup>35</sup>

The impact of adult death on the health of children is most severe in the poorest households. Ainsworth and Semali found that “the poorest children who are paternal orphans or who live in households with a recent adult death are significantly more likely to be reported ill, but the negative signs on most of the death-asset interactions indicate that the impact is less severe among households with greater wealth.”<sup>36</sup> Poor orphans had higher rates of mortality in their sample while paternal death raised the likelihood of orphan morbidity by 32% compared with non-paternal orphans also in low-asset households.<sup>37</sup>

Foster *et al* found that AIDS orphans in Zimbabwe were subject to isolation, discrimination and stigmatisation. AIDS orphans in this study were more likely to be maternal orphans,

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<sup>32</sup> *ibid* p. 834.

<sup>33</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” pages 3-4.

<sup>34</sup> “The Impact of Adult Deaths on Children’s Health in North-western Tanzania,” pages 6, 8.

<sup>35</sup> *ibid* pages 6, 9.

<sup>36</sup> *ibid* pages 20-21.

<sup>37</sup> “The Impact of Adult Deaths on Children’s Health in North-western Tanzania,” p. 28.

younger than other orphans, living in low-income areas, and out of school. Community members in the study reported that caregivers abused and neglected AIDS orphans, depriving them of food, clothing and school fees. Community members also reported that AIDS orphans were given excessive physical work and treated differently from the biological children within the household. Teachers also reported that they could identify the AIDS orphans by their lack of school fees, poor clothing and lack of food. The data set from the Foster *et al* study also showed that “AIDS is leading to an increasing proportion of maternal orphans and an increasing proportion of orphaned children under 5 years old.”<sup>38</sup> Their 1995 enumeration showed an orphan prevalence of 12.8% as compared to 6.8% in 1991. Most importantly, perhaps, was the finding that the care of orphans in the community often falls on individuals who have least resources.”<sup>39</sup>

In Zimbabwe, AIDS has been labelled “the grandmothers’ disease” because, according to Mutangadura, it is the elderly who bear the burden of caring for the sick and the survivors. This is care they perform with great difficulty due to their own limited wealth, education, capital and work opportunities. Not only are these grandmothers caring for orphaned children, they are also deprived of their own financial security by the loss of their own children – the parents of the orphans now in their care -- to AIDS. Without social and economic support in countries that provide little or no social security to the elderly, these grandparents invariably become destitute. The consequences for future growth are devastating with orphans entrenched in a cycle of poverty and limited potential for escape.<sup>40</sup>

In Zambia, too, the characteristic household response to AIDS was a “rapid transition from relative wealth to relative poverty.”<sup>41</sup> In the Nampanya-Serpell study, the shift was most evident for urban paternal orphans when the father was both the breadwinner and the tenant of a house provided by the employer. The family invariably had to move to a poorer dwelling without electricity or piped water and, once again, the children were removed from school. Although education was free, the fees for books, uniforms and transport went to the parents whose resources were constrained by medical, funeral and daily food expenses.<sup>42</sup> Though displacement was less of an issue in the rural sample, death of the father meant a critical loss of labour and food security, especially since the heads of households in the majority of instances of paternal death was the maternal grandmother.<sup>43</sup>

Though Lundberg, Over and Mujinja reported that Tanzanian orphans were also withdrawn from school due to lack of money for school fees, uniforms and supplies, they noted that infection rates were higher among the wealthy and better educated population than among the poor.<sup>44</sup> With wealthy families more likely to suffer a death in this sample, Lundberg *et al* were able to compare impact of adult death based on available resources. While the wealthier households had higher expenditures and higher consumption on all measured components, the poorer households showed a drop in food expenditure and consumption in the first six months following the adult death. The wealthier households in this study had an abundance of physical, human and social capital with a broader network of friends and relatives on which to

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<sup>38</sup> “Orphan Prevalence and extended family care in a peri-urban community in Zimbabwe,” pages 9-11,12.

<sup>39</sup> *ibid* p. 16.

<sup>40</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” p. 24, also M. Lundberg, M. Over, P. Mujinja, “Sources of Financial Assistance for Households Suffering an Adult Death in Kagera, Tanzania,” *South African Journal of Economics*, vol. 68, no. 5 (Dec 2000), p. 949.

<sup>41</sup> “Social and Economic Risk Factors for HIV/AIDS-Affected Families in Zambia,” p. 1.

<sup>42</sup> *ibid* pages 1-2.

<sup>43</sup> *ibid* pages 8-9.

<sup>44</sup> “Sources of Financial Assistance for Households Suffering an Adult Death in Kagera, Tanzania,” p. 949.

depend in a crisis. They were more likely to receive private assistance than were poor families and were better able to engage in common risk-pooling within a larger social network. The implication, according to Lundberg *et al* is that “the impact of the death is potentially even worse for poor households – not only are they hit harder, but they must bear a larger part of the burden alone.”<sup>45</sup>

## Coping Mechanisms

Throughout Africa, individuals and households have relied on the extended family to cushion the shock of adult death. Family networks have historically contributed goods and money to meet immediate needs, helped with funeral expenses and cared for orphans in the event of parental death. In Zimbabwe, the extended family as a safety net has been the most important community response to income crisis throughout history.<sup>46</sup> There is evidence, however, that the extended family is now under stress. In many countries, poor economies and the burden of mounting deaths from HIV/AIDS have severely compromised the extended family’s ability to contribute to the security of households suffering adult death.<sup>47</sup>

While this section will rely heavily on evidence of extended family coping mechanisms in Zimbabwe, it is important to note that South African families may be compromised to an even greater degree than families in other African countries. Apartheid was responsible for disrupting both family and community life and weakening traditional coping mechanisms that may still be strong in other countries. Rapid urbanization and migration have further weakened informal support networks. It is also possible to argue that the expectation of health care and support from the state has contributed to the weakening of traditional systems. Many South African families do indeed rely on old age pensions, Child Support Grants, and other social support grants to cope with financial crises and meet survival needs. This report will not argue that social support grants weaken already strong family and community networks for on simple reason: These networks, weakened by Apartheid, have become weaker still due to the impact of adult death from the HIV/AIDS epidemic. What is apparent in Zimbabwe also holds true in South Africa. South African families and communities need monetary and community-based assistance in order to cope with the levels of death, illness and poverty resulting from this current epidemic.

Some researchers claim that the extended family in parts of Africa is breaking down under the weight of the current death burden.<sup>48</sup> Some of these studies, in turn, emphasize the need for innovative mechanisms and non-traditional strategies for coping with the failures of families to care for orphans. While there may indeed be a need for alternative institutions such as foster care, orphanages, and day care centres, Foster *et al* argues that such alternatives may, in fact, contribute to undermining extended family coping mechanisms. Foster argued in 1995 that the extended family coping mechanism in Zimbabwe was still strong, as evidenced by the fact that 99% of all orphans in their study were cared for by extended families within the community. 84% of these orphans were cared for by maternal kin with 16% cared for by the paternal family.<sup>49</sup> In their 1998, however, Drew, Foster and Makufa acknowledged that the extended family was demonstrating great difficulty in caring for orphaned children in areas of

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<sup>45</sup> *ibid* p. 978.

<sup>46</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” p.8.

<sup>47</sup> *ibid* p.31,

<sup>48</sup> “Impending Catastrophe Revisited: An update on the HIV/AIDS Epidemic in South Africa,” p. 10.

<sup>49</sup> “Orphan Prevalence and extended family care in a peri-urban community in Zimbabwe,” pages 5, 9.

very high infection. The burden of care in this study, and increasingly in all areas hardest hit by HIV/AIDS, was falling to the elderly and adolescents.<sup>50</sup>

In Zimbabwe, child-headed households are indicative of a family under stress. For the majority of these children, their relatives are unwilling to take care of them. Mutangadura points to the negative impact on the family's living standard as the reason for refusing to take in orphans. Limited in the amount of love, time, and space for extra children, these relatives are over committed with too many other sick and dying family members. "In localities where prevalence of AIDS is very high and many families are affected," Mutangadura notes, "the capacity of the social capital to provide for the needy is severely curtailed."<sup>51</sup> She does not advocate orphanages, however, as they are too costly and not in the best interests of the children. Not only does removal to orphanages isolate children from their communities and hinder their socialization, it jeopardizes their right to inherited land and denies them their sense of belonging within the community.<sup>52</sup> Though children may be stigmatised and left to care for themselves following an adult death, orphanages do not present as a viable alternative. The fact is that most children, as previously stated, are cared for by elderly relatives (usually the maternal grandmother) upon the death of one or both parents. In Mutangadura's study, 62% of the heads of foster households were female with 60% being grandparents, 25% another relative, 13% adolescent and 2% child-headed. 40% of all female foster household heads were age 60 or over. The responsibility of caring for orphaned children clearly diverts resources from the maternal family and places undue burdens on elderly women with only limited means of earning income. Though the maternal family was also responsible for meeting funeral costs in 80% of the adult death cases, 24% of households sold assets to cover funeral costs, remarriage, food and school fees as well.<sup>53</sup> Foster *et al* notes that the maternal family's responsibility for orphans upon parental death is a departure from a tradition that, until recently, dictated that widows and children be cared for by the paternal family. Not only does the paternal side now decline care, but should the paternal aunts take in orphans, they are reportedly more likely to exploit their charges. Finally, the paternal family, while denying the widow remarriage to a sibling in her husband's family as was the custom, is also likely to take possession of the husband's property and deny the survivors of resources necessary for survival.<sup>54</sup>

Dominant coping strategies used by surviving family members dealing with decreased income due to adult death include reducing consumption or elimination of food items, decreasing meals to one meal at night time, selling assets, engaging in informal business activities, utilizing child labour, and borrowing from family or other sources. Approximately half of all those questioned in both the urban and rural sample in the Zimbabwe study asked extended family and community members for assistance with food and money. A relatively small percentage requested aid in the form of clothing, credit or child fostering. 95% of households at both sites reported that help of any sort was not easily obtainable.<sup>55</sup> Focus groups reported that communities rarely helped with school fees, medical fees or rent. "Both key informants and focus group discussion participants," according to Mutangadura, "pointed out that

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<sup>50</sup> "Strategies for Providing Care and Support to Children Orphaned by AIDS," p. S10.

<sup>51</sup> "Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development," pages 8-9.

<sup>52</sup> *ibid* p. 9.

<sup>53</sup> *ibid* pages 11, 15.

<sup>54</sup> "Orphan Prevalence and extended family care in a peri-urban community in Zimbabwe," pages 13-14.

<sup>55</sup> "Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development," pages 19-20

community help was not forthcoming anymore because of inflation, lack of money, because of high unemployment, and too much commitment as everyone is being affected by the high morbidity and mortality” of the HIV/AIDS epidemic.<sup>56</sup>

Family networks may still be strong, as Foster *et al* report, but it is clear from the Zimbabwe study that both families and communities, once able to cope with low to moderate levels of household shock, are failing to meet the needs of needy households. Both families and communities need external support in order to assist those households struggling to cope with multiple deaths from HIV/AIDS.<sup>57</sup> Drew, Makufa, and Foster argue that large numbers of orphans can still be supported within their own communities with governmental assistance. Programs such as the Zimbabwe Department of Social Welfare sponsored FOCUS model that identify orphans, utilize volunteers within the community, and promote community-based self-reliance are both cost effective and preferable to removing orphans from the community.<sup>58</sup>

Mutangadura also advocates community self-help projects that move children into self-sustenance and away from relief. Many of the urban women in her study, especially elderly foster grandmothers, turned to informal business activities such as food vending and urban agriculture to cope with income shortages but were faced with high competition and lack of resource to purchase goods. Micro-credit was not used in such communities due to prohibitive interest rates. One could argue that an infusion of money into this sort of scenario would boost informal business and enable these families to better sustain themselves. In the rural sample, grain saving schemes proved an important source of community support, mitigating the loss of an adult in the household. For this population, Mutangadura suggests that contribution of seed and fertilizer would be an appropriate means of providing much needed assistance.<sup>59</sup>

## Malnutrition

All children born to HIV positive mothers carry antibodies to HIV at birth. Approximately 30% of infants born to seropositive mothers in Sub-Saharan Africa will test positive themselves by the age of 12 months (the time when the mother’s antibodies leave the child’s system).<sup>60</sup> And the rate of HIV prevalence among pregnant women is on the rise. In Soweto, South Africa, for instance, the antenatal prevalence of HIV rose from 6.4% to 22.5% between the years 1994 and 1998.<sup>61</sup> According to Thea *et al*, approximately 80% of all HIV-infected children in Sub-Saharan Africa die by the age of five, with diarrhoea being the most frequently reported cause of death for children up to the age of 18 months (over 50%). In Rwanda, diarrhoea accounted for up to 60% of all illness in HIV-infected children, affecting 80% of all HIV-infected children in their second year of life.<sup>62</sup>

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<sup>56</sup> *ibid* p.20.

<sup>57</sup> *ibid* p.20.

<sup>57</sup> “Strategies for Providing Care and Support to Children Orphaned by AIDS,” pages S10-S13.

<sup>59</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” pages 21-22.

<sup>60</sup> R.E. McKinney, J.W.R. Robertson and the Duke Paediatric AIDS Clinical Trials Unity. “Effect of Human Immunodeficiency Virus on the Growth of Young Children.” *Journal of Paediatrics* 1993, vol.123, p. 580.

<sup>61</sup> T.M. Meyers, *et al*. “Paediatric Admissions with Human Immunodeficiency Virus Infection at a Regional Hospital in Soweto, South Africa,” *Journal of Tropical Paediatrics*, Vol. 46 (August), Oxford: Oxford University Press, 2000, p. 224.

<sup>62</sup> D.M. Thea, St Louis, M.E.; Atido, U. *et al*. “A Prospective Study of Diarrhoea and HIV-1 Infection Among 429 Zairian Infants,” *New England Journal of Medicine* 1993; vol. 329, p. 1696.

These are very grim statistics for an area of the world already plagued by poverty and malnutrition. The HIV epidemic has had a serious detrimental affect on the health of young children already struggling for their very survival in the poorest sections of Sub-Saharan Africa. This section will assess the affects of both the mother's and the child's HIV status on the health of children in Sub-Saharan Africa. The goal is to integrate data from medical studies with evidence from household surveys for a better picture of the relationship between HIV, poverty and malnutrition.

As previously noted from the Ainsworth study in Kagera, Tanzania, the presence of HIV in the household raises the likelihood of exposure to other infections. Exposure to infection, in turn, raises the risk of malnutrition for young family members. "Morbidity and malnutrition," states Ainsworth, "have a synergistic relationship. Illnesses such as tuberculosis, diarrhoea, and measles, have well-documented biological effects on worsening children's nutritional status, while severely malnourished children have higher morbidity and mortality."<sup>63</sup> Malnutrition in and of itself can cause immuno-supression in young children by inhibiting host defences, impairing tissue repair functions, and compromising the body's ability to resolve attacks of acute diarrhoea.<sup>64</sup> It is therefore difficult, even with HIV positive infants, to distinguish whether the cause of increased immuno-supression is the virus or the resulting malnutrition. "In either event," states Thea *et al*, "the cyclic effects of diarrhoea, malnutrition, and immune dysfunction can produce an accelerated downward course" for infected infants with persistent diarrhoea.<sup>65</sup>

Some medical studies, such as that conducted by E.T, Taha *et al* in urban Malawi, indicate that "maternal HIV infection is the main determinant of mortality in the first 30 months of life."<sup>66</sup> The mortality rate of children born to HIV-infected mothers was, in this study, three times higher (36% as compared with 12%) than those born to seronegative mothers, even though many of these infants had normal birth weights. Low birth weight (along with intra-uterine growth retardation (IUGR) and prematurity) has traditionally been considered a major determinant of child survival, yet this data suggests that birth weight may no longer be a reliable indicator for development and growth of infants born to HIV positive mothers. Children born to sero-negative mothers had a higher probability of survival over their first 30 months while children born to sero-positive mothers were more likely to die from pneumonia, fever, failure to thrive and diarrhoea.<sup>67</sup> Again, most of these infants had normal birth weights. Those infants born to sero-positive mothers who were themselves sero-positive had the lowest survival possibilities at 12 months of age.<sup>68</sup>

Excess mortality in infancy and early childhood is consistent in studies of infants born to sero-positive mothers throughout Africa.<sup>69</sup> Bailey *et al*, in a prospective study of over five hundred children in the Democratic Republic of Congo, found that mother's HIV status had a direct affect on her ability to care for her children. "In Congo," according to Bailey's 1999 study,

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<sup>63</sup> "The impact of adult deaths on children's health in North-western Tanzania," pages 6, 10.

<sup>64</sup> "A Prospective Study of Diarrhoea and HIV-1 Infection Among 429 Zairian Infants," p. 1701.

<sup>65</sup> *ibid* p. 1701.

<sup>66</sup> E. T. Taha, *et al*, "The Effect of Human Immunodeficiency Virus Infection on Birth weight, and Infant and Child Mortality in Urban Malawi," *International Journal of Epidemiology*, 1995, Vol. 24, No. 5, p. 1027.

<sup>67</sup> "The Effect of Human Immunodeficiency Virus Infection on Birth weight, and Infant and Child Mortality in Urban Malawi," p. 1024.

<sup>68</sup> "The Effect of Human Immunodeficiency Virus Infection on Birth weight, and Infant and Child Mortality in Urban Malawi," p. 1025.

<sup>69</sup> *ibid* p. 1027.

“uninfected children of sero-positive mothers suffer nearly twice the incidence of persistent diarrhoea as uninfected children of sero-negative mothers and the incidence of infant diarrhoea increases with severity of maternal disease.” Bailey *et al* concluded that the mother’s disease led to “increased risk in their children for under-nutrition, diarrhoea, and respiratory infections that would likely retard growth progression.”<sup>70</sup> The infected children, however, suffered significantly more stunting (low height for age), wasting (low weight for height) and under-nutrition than did their uninfected cohorts ages 0-18 months.<sup>71</sup> Once again, the cycle was apparent.

Persistent diarrhoea was strongly associated with malnutrition and HIV infection in Congolese children as it was for the children in Soweto. The more severely wasted the child was prior to the diarrhoeal episode, the more vulnerable he was to subsequent episodes as compared to less wasted children.<sup>72</sup>

Persistent diarrhoea, according to Thea *et al*, is likely to occur earlier in infected than uninfected infants. In their prospective study of over 400 Zairian infants, 45 deaths occurred in infants whose HIV status was known. Of these deaths, 24% were due to persistent diarrhoea and 91% occurred in HIV-infected children. Diarrhoea was the leading cause of death in the cohort (36%) but for HIV positive children, the mortality rate from diarrhoea increased by 11 fold.<sup>73</sup> Children whose mothers’ were symptomatic of AIDS disease had higher incidence of diarrhoea though the risk of persistent diarrhoea increased for uninfected infants whose mothers had died of AIDS (but not those whose mothers were sick). The risk of persistent diarrhoea increased for infected infants as well if the mother was either symptomatic or had died.<sup>74</sup> Thea, like Bailey, asserted that morbidity “and by implication mortality, was related to the ability of the mother to care for her infant and maintain infant hygiene and nutrition, especially during episodes of acute diarrhoea needing increased attention.”<sup>75</sup>

The Zairian sample is but one study that provides quantitative estimates of the effect of HIV-1 infection of rates of disease and death among infants. In short, “episodes of acute, recurrent, and persistent diarrhoea occurred significantly more frequently among infected infants than among uninfected controls.” The significance here lies in the fact that such “repeated episodes of acute diarrhoea often lead to increasingly severe protein-energy malnutrition, specific micronutrient deficiency. . . or a combination of the two.”<sup>76</sup>

Thus, even if the child is uninfected with the virus, the mother’s illness with AIDS-related infections is likely to create a situation in which the child is more susceptible to diarrhoea which in turn leads to malnutrition, which then compromises the child’s ability to resolve the acute diarrhoea which then increases the child’s risk of death. If the child is also infected, his system will inevitably be immuno-suppressed not simply by malnutrition but by the virus as well, furthering raising the risk of death. Interventions that delay the morbidity and mortality

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<sup>70</sup> Robert C. Bailey, *et al*, “Growth of Children According to Maternal and Child HIV, Immunological and Disease Characteristics: A Prospective Cohort Study in Kinshasa, Democratic Republic of Congo,” *International Journal of Epidemiology* (1999), Vol. 28,p. 537.

<sup>71</sup> “Growth of Children According to Maternal and Child HIV, Immunological and Disease Characteristics: A Prospective Cohort Study in Kinshasa, Democratic Republic of Congo,” p. 537.

<sup>72</sup> *ibid* p. 537.

<sup>73</sup> “A Prospective Study of Diarrhoea and HIV-1 Infection Among 429 Zairian Infants,” p. 1700.

<sup>74</sup> *ibid* pages 1698, 1701.

<sup>75</sup> *ibid* p. 1701.

<sup>76</sup> “A Prospective Study of Diarrhoea and HIV-1 Infection Among 429 Zairian Infants,” pages 1700-1701.

of the HIV-infected mother could thus, significantly contribute to the long term survival of uninfected children of infected mothers.<sup>77</sup>

In the Soweto, South Africa study, T.M. Meyers *et al* assessed both the HIV and nutritional status of 92% of all children under the age of five admitted to the Chris Hani Baragwanath Hospital (CHB) from June to December of 1997 (507 of 549 admitted) and found an HIV prevalence of 22.9%. Of the 507 tested, 66.9% of the uninfected children were well-nourished while only 34.3% were well-nourished of those children who were HIV positive. 29.4% of the infected children had marasmus (emaciation) or marasmus-kwashiokor (protein-energy malnutrition with oedema) as compared with 4.7% of the uninfected children.<sup>78</sup> Without citing diarrhoea as a factor, this study noted that “infectious disease and associated malnutrition were the most common reasons for admission in HIV infected children.” 76% of the infected children who died were malnourished at the time of death, with over 50% being severely malnourished. Of those who died uninfected with HIV, 53% were nutritionally compromised but only two were severely malnourished.<sup>79</sup>

McKinney *et al*, in a retrospective analysis of 170 children under the age of 25.5 months, found that HIV infected children were proportionately smaller than the uninfected controls. These children, though not malnourished, “were appropriately proportioned but were the size of children younger than their chronological age.”<sup>80</sup> By the age of four months, HIV-infected children were significantly smaller in both weight-for-age and height-for-age. Thus, the infected children in this study were neither lean nor wasted, but even with proper nourishment, did not experience normal growth. McKinney *et al* suggest a physical rather than a social cause. It is possible, he asserts, that the HIV-infected infant uses more energy at rest while receiving a caloric intake comparable to an uninfected child. While this study appears unrelated to poverty and malnutrition, it does point to the fact that HIV-infected infants may require even more calories and nutrients than uninfected infants – a requirement that impoverished mothers can not meet without adequate assistance.

Several household studies have attempted to assess nutritional status of HIV-infected children as well. In the Zambia study, researchers used the mid-upper-arm-circumference as the principle index of nutritional status in children ages 0-5, noting that it is “widely regarded as one of the most reliable measures of protein-calorie malnutrition in early childhood.” Weight for Age was used for verification. Although the expectation was that socio-economic status would have a large effect on the nutritional status of AIDS affected children, this turned out not to be the case in the rural sample. The most significant variable here was age: the younger the child, the worse the nutritional status. In the rural sample, the number of children in the household was also negatively related to their nutritional status while in the urban sample, the socio-economic status of the care giving family did have “a significant protective effect on the health status of the orphans.” Why it was that “malnutrition was found among the youngest children in economically better off families as well as poorer families” is difficult to explain. It is possible that these young children were recent additions to the household, orphaned by AIDS-related deaths. If so, their malnutrition could have preceded their entry to the household.

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<sup>77</sup> *ibid* p. 1701.

<sup>78</sup> “Paediatric Admissions with Human Immunodeficiency Virus Infection at a Regional Hospital in Soweto, South Africa,” pages 224-226.

<sup>79</sup> *ibid* p. 228

<sup>80</sup> R.E. McKinney, J.W.R. Robertson and the Duke Paediatric AIDS Clinical Trials Unity. “Effect of Human Immunodeficiency Virus on the Growth of Young Children.” *Journal of Paediatrics* 1993, vol.123, p. 582.

Ainsworth, as previously mentioned, used morbidity, height-for-age (stunting) and weight-for-height (wasting) on the day of the interviews to measure child health. These children were also reported to be stunted at almost the same rate in the poor and better off households.<sup>81</sup> She found that 37% of her sample were stunted, 2% were wasted and 1% were both stunted and wasted, noting that stunting and wasting reflect very different types of nutritional deficits. Wasting reflects stress at the time of interview and is relatively easy to reverse whereas stunting is the result of cumulative stress and reduced growth rates and is much slower to recover.<sup>82</sup>

Data regarding malnutrition in AIDS-affected households or AIDS-infected children must be regarded cautiously. In many of the countries cited by these studies, protein-energy malnutrition (PEM) was prevalent prior to the AIDS epidemic. Nevertheless, it is clear that Paediatric AIDS brings with it symptoms of weight loss and protracted diarrhoea. Failure to thrive, is in fact, the most consistent symptom of HIV-infected children.<sup>83</sup> What is also clear is that HIV infection in the mother and in the child is making worse an already desperate problem of malnutrition in Sub-Saharan Africa. If poor women and children were considered the most vulnerable members of society prior to the AIDS outbreak, it would appear that their status as a group has worsened considerably.

## Mitigation

According to Mead Over, government intervention is justified if it improves social welfare and if such improvement would not occur without the specified intervention. In order to evaluate a given intervention, therefore, it is necessary to characterize a situation in the absence of the proposed intervention.<sup>84</sup> That has, in part, been the object of this research. Sub-Saharan Africa is an area of the world riddled with poverty, malnutrition and social inequity, even in the absence of the HIV/AIDS epidemic. HIV/AIDS has exacerbated all three of these problems while poverty, malnutrition and social inequity have made certain people more vulnerable to the impact of HIV. The one point on which all researchers in this study agree is that mitigation efforts, whether designed to assist orphans, caretakers or households, should focus on the problem of poverty and not the specific problem of AIDS.

The 1993 pilot program in Zimbabwe, FOCUS (Families, Orphans, and Children Under Stress) did not differentiate between AIDS orphans and other orphans. It targeted those most in need with community-based interventions that enabled local communities to better support orphan populations.<sup>85</sup> Foster *et al* advocate the need to support orphans within their own communities. Advocating a more thorough and systematic method of orphan enumeration, they agree there is merit in considering relief of all orphans and not AIDS orphans per se. Their prediction is that an inclusive policy could reduce the discrimination, prejudice and stigmatisation associated with being an AIDS orphan, while raising awareness of the need for community-based initiatives.<sup>86</sup> Although Foster *et al* warn against undermining community

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<sup>81</sup> "Social and Economic Risk Factors for HIV/AIDS-Affected Families in Zambia," pages 11,12,16.

<sup>82</sup> "The impact of adult deaths on children's health in North-western Tanzania," p. 10.

<sup>83</sup> J.B. Kurawige *et al*, "HIV-1 Infection Among Malnourished Children in Butare, Rwanda," *Journal of Tropical Paediatrics* 1993; vol. 39, pages 94-95.

<sup>84</sup> Mead Over, "The Public Interest in a Private Disease: An Economic Perspective on the Government Role in STD and HIV Control," *Sexually Transmitted Diseases*, eds King K. Homes, et al, McGraw-Hill, 1999, p. 3.

<sup>85</sup> "Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development," p.10.

<sup>86</sup> "Orphan Prevalence and Extended Family Care in a Peri-urban Community in Zimbabwe," p. 15.

support mechanisms by raising expectations of formal assistance without benefit, they also point to the underlying strength of the community. That orphans are now being cared for by elderly maternal relatives they consider to be adaptive rather than a sign of family decay. “The fact that community coping mechanisms are changing does not imply that the extended family method of caring is about to break down,” they state, but rather that the family is accommodating to a changing society. Foster is concerned that those who emphasize the breakdown of the extended family and support institutional care as an alternative could encourage family members to relinquish their responsibility for caring for orphans within the community.<sup>87</sup>

Mead Over agrees that targeting support for orphans should be broadly based. “To the extent that poor orphans can be identified,” he states, “they can be a particularly useful target group for antipoverty safety net policies or for policies designed to mitigate the impact of the epidemic.” Where equity is the concern, according to Over, it is important to “target assistance efforts to the poorest orphans, regardless of the cause of their parents’ death.”<sup>88</sup> Ainsworth and Semali find that children in the poorest household are the ones most severely affected by adult death. “Both maternal and paternal orphans,” according to their data, “are substantially more likely to be short for their age: the loss of a parent raises stunting among the non poor to levels found among poor children with living parents; among the poor, orphanhood raises stunting even higher.” They agree, therefore, that interventions should be targeted to the poorest households since these are the families hit the hardest by adult mortality. “Targeting health interventions solely to orphans or children in households with a recent adult death,” moreover, “would miss many children with equally severe” poverty related health problems, and benefit children in households that have adequate resources.<sup>89</sup> Mutangadura, based on her study, also agrees that “the orphan problem needs to be considered in the context of poverty.”<sup>90</sup> The government, she argues, must target social welfare assistance to the most needy, regardless of the immediate cause of poverty. She predicts that social welfare assistance to highly vulnerable households will result in improvements in child welfare, more adequate nutrition and access to education.

While recommending specific nutrition supplementary programs be provided to needy children at schools and clinics, she also suggests that mitigation take gender into consideration.<sup>91</sup> Because elderly grandmothers are disproportionately affected by premature female deaths in her study, she recommends targeting assistance directly to elderly women raising orphans.<sup>92</sup>

Public and private transfers, where available, are a critical means of assisting elderly women and poor households in overcoming the shock of adult death. In Tanzania, for instance, households with a recent death receive more assistance through government, Non-Governmental Organizations and formal institutions than do households without a recent

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<sup>87</sup> *ibid* p.16.

<sup>88</sup> Mead Over, “The Public Interest in a Private Disease: An Economic Perspective on the Government Role in STD and HIV Control,” *Sexually Transmitted Diseases*, eds King K. Homes, et al, McGraw-Hill, 1999, p. 8.

<sup>89</sup> “The impact of adult deaths on children’s health in North-western Tanzania,” pages 31-32.

<sup>90</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” p. 26.

<sup>91</sup> Kurawige et al also advocate aggressive nutritional support to prevent PEM in HIV-infected children in households where proper nutrition is unattainable due to poverty and premature death of the parents. “HIV-1 Infection Among Malnourished Children in Butare, Rwanda,” p. 95.

<sup>92</sup> “Household Welfare Impacts of Mortality of Adult Females in Zimbabwe: Implications for Policy and Program Development,” pages 12, 24, 26.

death. In the absence of government transfers, moreover, a family with greater physical resources available will have access to private transfers from informal family and community networks, whereas the poorer family without assets is forced to rely more on credit at high interest rates to meet its needs.<sup>93</sup> According to Lundberg, Over, and Mujinja, “government and non-government agencies made a substantial difference to resource poor households which had suffered an adult death in Kagera, Tanzania in 1990-1994.”<sup>94</sup> More than one third of the assistance to poor households within the first month following an adult death was formal, making the assistance quite substantial in absolute terms.

The data from the studies used in this review support the need to strengthen governmental grants that alleviate poverty. Social support grants already in place in South Africa, such as the old age pension, the Child Support Grant, and the Disability Grant can all work to improve the welfare of those suffering the greatest impact from the HIV/AIDS epidemic. The elderly, having lost the traditional financial security from their own offspring on which most elderly rely, must now support grandchildren who may themselves be sick with AIDS. It is safe to say that an orphan living with a grandparent in a country that provides an old age pension is significantly better off than one residing in a country that does not. The Child Support Grant, were it to be efficiently distributed, could also substantially improve the welfare of children suffering the loss of a parent. It is clear from the research evidence that the youngest children are the most vulnerable to malnutrition in the event of a parental death. Yet providing assistance for children up to the age of seven may not be enough. Children whose parents have died of AIDS (or any other means) need continual support in order to avoid being exploited, abandoned or sent out into the streets. There is evidence, however, that in poor rural areas children suffer more malnutrition with greater numbers of children in the household. The grant should not be seen as an incentive to take in extra children. Rather it should be a means of holding families and communities together as the data also suggests that children living with other than a close relative are subject to more exploitation than those supported by their kin.

The Disability Grant is one area in which it may prove helpful to focus specifically on AIDS. Providing assistance to those unable to care for themselves or others, this grant would appear to be a critical part of the solution to maintaining child health in the AIDS-affected household. To what extent the people who qualify as “disabled” are suffering with AIDS may be difficult to determine due to the lack of testing and stigmatisation involved in discussing the disease. Yet the risk of malnutrition for poor children rises substantially if the mother is sick with AIDS. We know, based on these studies, how AIDS manifests, how it can be identified as the cause of death, and how it impacts the poor household when it strikes. It is clear that education and prevention are of the utmost importance, yet equally critical to the welfare of children suffering from the impact of AIDS in South Africa may be qualifying households affected with AIDS for Disability Grants.

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<sup>93</sup> “Sources of Financial Assistance for Households Suffering an Adult Death in Kagera, Tanzania,” p. 978.

<sup>94</sup> *ibid* p. 980.

## **Chapter 3 The Mount Frere Case Study – Methodological Issues**

### **The study area**

The study was undertaken in Mount Frere, part of region E of the Eastern Cape. The region is comprised of former areas of the Transkei Bantustan with two magisterial districts called Kwabacha and Tabankulu.

### **The Demography of Poverty in the Eastern Cape**

The Eastern Cape is composed predominantly of Africans, who comprise approximately 86% of the population followed by Coloured, who comprise 7%, Whites who comprise 5% and the remaining Indians (under 1%) with the remainder “unspecified” (State of South African Population Report, 2000: 73).

In the Eastern Cape the percentage of the population who are non-urban are 63.4 percent compared to 36.6 percent who are urban inhabitants (State of South African Population Report, 2000: 73).

There is a high prevalence of poverty, chronic illness, including those associated with HIV/AIDS and infant and child deaths. The poverty rate, or measure of absolute poverty in the Eastern Cape is 74.3 percent compared to 45 percent for the whole country whilst the Eastern Cape’s low human development index at 0.596 exceeded only by the Northern Province at 0.531 compared to 0.628 for the entire country. (UNDP, Transformation for Human Development: 2000) The Eastern Cape also has the highest infant mortality rate, numbering 55 of every 1000 live births compared to a South African average of 41 per 1000 live births (State of South African Population Report, 2000: 73).

The infrastructure is rudimentary. Only 22 percent of households in the Eastern Cape have access to safe water from an internal household tap compared to (an itself very low) South African average of 40 percent. Only 30 percent of households receive electricity direct from the authority, the lowest in the country and compared to a national South African average of 55 percent. The use of paraffin as an alternative heating source constitutes 37 percent of the total, again the highest use of such a heating source in the country. Only 31 percent of households have refuse removed weekly by the local authority with 23 percent of households registering no refuse disposal compared to a South African average of 11 percent (State of South African Population Report, 2000: 73).

The broader population is dispersed across the rural areas, with no defined centre and thus the inaccessibility of transport has a dramatic effect on the ability of users to engage with government services or to be reached by such services. Only 16 percent of households have access to in on-site phone with 45 percent registering no access to telephonic services, the highest in the country and compared to 18 percent national average registering no such access.

Of particular note to this study is the fact that the Eastern Cape has the highest rate of unemployment in the country at 48.5 percent with only 50.8 percent of males and 49.2 percent of females being economically active (State of South African Population Report, 2000). This high rate of unemployment makes households heavily dependent on remittances and

government support through social security if they are to sustain their livelihoods. The high rate of households headed by women in the Eastern Cape, (50 percent compared to a South African average of 38 percent) means that there is a gender dimension to the economic impact on households of chronic illness, including HIV/AIDS. For these substantive reasons the area was chosen.

There were also logistical factors that made the site suitable for this study. Due to the short time-frame of the research there was a concern to commence the field-work, and engagement with the households, as soon as feasible. Given that the topic area was very sensitive, concerning details of household income and expenditure and the impact of illness on the household, it was felt that building on past related research in the area with a knowledgeable, experienced researcher well known to the area, would improve the response rate and quality of the data.

### **The study sample of thirty households**

The study sample of thirty households was derived from households who had admitted a child made ill by severe malnutrition to either Mary Terese or Sipetu hospitals in the Mt. Frere Health District (Mt. Frere & Ntabankulu Sub-Districts). These children were accompanied by their parents for the duration of their hospital stay and it was during this time that consent was sought from the parents for recruitment into the study.

The targeted sample size was 30 households. By the end of the study period 43 households had been recruited to yield the desired sample of 30 households. 26 of the households were recruited from Sipetu hospital (Ntabankulu Sub-district), which is consistent with higher rates of malnutrition recorded in this sub-district. Home visits to each individual household in the sample were completed between the months of September to December 2001. Of the thirteen households recruited, but not included in the final sample, two were visited and found not to be available for interview, and eleven were never visited as the desired sample had been reached. These households were from similar areas to the final sample.

### **Recruitment of the sample**

Prior to the study starting, permission was obtained from the health district manager to conduct the study in the two hospitals of the Mt Frere Health District. The research was then introduced to the most senior authorities in the hospitals at the time. In Mary Terese the chief executive officer was contacted and in Sipetu Hospital the matron in charge was approached.

In the two hospitals, carers (usually mothers) of children who are admitted for malnutrition are encouraged to stay with their children during hospitalisation. The average period of stay in hospital is 2 weeks.

During the recruitment period, the field-work researcher visited the hospitals 1-2 times per week. All caregivers of new child arrivals who were severely malnourished and who were present and available at the time of the visit would be approached. Privacy and confidentiality were observed by interviewing the carers in a private room in the hospital ward. All interviews were conducted in the local language, Xhosa.

The purpose of the study was explained to all recruits and permission to visit their homes after discharge was also sought. It was made explicit that participation to the study was on a

completely voluntary basis, and that refusal to participate would not have any repercussions on hospital treatment.

Verbal consent was obtained from each participant who were then asked to provide details of their addresses (all the homes in the area do not have formal addresses). There were no refusals in the group. It was explained that due to a specified targeted number, it might not be possible to reach everybody who had consented. The caregivers were requested to inform their families once they go back home of the potential visit of the researcher and its purpose.

The recruitment period lasted from June and until October 2001.

### **Development of the data gathering tools:**

The methodology developed for the study had two components. First an elaborate structured household questionnaire was developed which would enable data on household structure, illness patterns among household members, income and expenditure to be recorded and codified. In due course this would enable quantitative analysis using statistical analysis software. Early exploration in the field made it clear that direct administration of such an instrument was alien to the experience of the study population, would produce interviewee 'fatigue' and in any event was not the a good way to elicit sensitive information. This led the research team to modify the data collection technique. The household questionnaire became the secondary data collection instrument and it was decided that a second instrument – consisting of an interview schedule - would be developed as the primary data collection tool. This primary data collection tool would allow a discursive depth interview covering the major areas covered by the household questionnaire. From the depth interview conducted in this way the researcher would be able to complete the detailed household questionnaire for later quantitative analysis. Another advantage of such a dual approach was that the primary data collection instrument allowed the gathering of rich qualitative data to further elucidate the research questions.

The first draft of the structured questionnaire was developed drawing on a wealth of existing national and international experience. Particular use was made of national and international research examining income and expenditure patterns of households affected by chronic illness, including HIV/AIDS. The field researcher, who had an intimate knowledge of the households in the study area, was closely involved in the development of the questionnaire. This was undertaken through intensive discussion in Mount Frere, a workshop in Durban, and email and telephone contact with the research co-ordinator and rest of the study team. The themes and questions were clarified to avoid any ambiguity and misinterpretation. The questionnaire tool was developed in English and the questions translated into Xhosa by the field researcher when conducting the interview. The English text was thus closely related to the corresponding Xhosa translation. The structured questionnaire was accompanied by an interview schedule covering the main topic areas of the questionnaire.

The interview schedule was developed to allow a "narrative" on household circumstances to emerge from each individual household visited – which could then be rigorously coded in to the structured questionnaire synchronously with or shortly after returning from the field using field notes. We believe this method allowed for high quality data-gathering that was responsive to the research conditions and provided interviewees to relay their accounts in a method most familiar to their daily lives.

## **The interview process**

All households were visited by the same field researcher. Visits were not announced or scheduled in advance. Upon arrival the field researcher would ask for the caregiver she encountered in hospital. If the caregiver was not available, but still resided in the household, then the researcher would return on another day. If the caregiver was at home then the researcher would remind them of the purpose of the study and obtain verbal consent again to conduct the interview. In some cases, where the caregiver was not available, other adult household members were asked if they would be willing to participate, after having the research explained to them. Each interview took 1.5-3 hours to complete. Interviews were conducted in the household and were not necessarily conducted in private as other household members were often called upon to assist with answering questions as noted below.

A depth interview was conducted in Xhosa using the interview schedule. Detailed notes were taken which yielded qualitative data and information to complete the household questionnaire. It is important to note that in most of the households there was more than one informant. In some instances, the key informant (generally the caregiver or mother of the malnourished child) would refer to other members of the family who would have better understanding or explanation of certain questions asked.

After the interview, a detailed summary of the household 'dynamics' was written up in for future reference. Post-interview summaries and additional notes were added the same day or within three days of the interview.

## Chapter 4 The Mount Frere Case Study – Findings

This study was an exploratory one. It has yielded important information on possible methodological approaches in this area and important qualitative information on the impact of chronic illness on family poverty and on the role of social security transfers in alleviating poverty. The data collected from the household questionnaires has proved to be robust and capable of quantitative analysis. However, the sample recruited was purposive, not random, and was small. It is therefore unwise to over interpret or analyse the quantitative data collected and to present the findings in a way which suggests statistical significance.

Moreover, it should be noted that the following does not include an analysis of the income dynamics of households. Although the data suggests this is feasible insufficient resources and time precluded an adequate analysis of this data.

Having given these caveats, this chapter presents some descriptive information from the quantitative analysis which are, at the least, suggestive of areas where widespread quantitative research would be fruitful.

### **The data analysis procedure.**

Data were obtained both at an individual level and a household level. Individual cases contained data on the adult and child population in each household as well as information on remitters and remitees in these households. Household data contained information on household assets and expenses as well as details about the status of the household regarding social security benefits.

Data from the largely pre-coded questionnaires were cleaned and analysis undertaken in SPSS.

### **Description of Sample**

The study population comprised a total of 103 adults of whom 37 were men and 66 were women. The children numbered 134 in total of whom 62 were girls and 71 were boys<sup>95</sup>. The following table illustrates the household composition:

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<sup>95</sup> Sex of one child not disclosed

**Table 4.1: Household Composition**

| Household identification number | No. of Adults | Age of Youngest Adult | Age of Eldest Adult | Average Age of Adult | No of Children | Age of Youngest Child | Age of Eldest Child |
|---------------------------------|---------------|-----------------------|---------------------|----------------------|----------------|-----------------------|---------------------|
| 1                               | 5             | 21                    | 67                  | 33                   | 4              | 1                     | 18                  |
| 2                               | 6             | 19                    | 61                  | 33                   | 9              | 3                     | 16                  |
| 3                               | 1             | 28                    | 28                  | 28                   | 2              | 2                     | 4                   |
| 4                               | 3             | 28                    | 70                  | 46                   | 3              | 2                     | 6                   |
| 5                               | 2             | 20                    | 36                  | 28                   | 2              | 1                     | 5                   |
| 6                               | 2             | 20                    | 46                  | 33                   | 2              | 2                     | 5                   |
| 7                               | 2             | 36                    | 56                  | 46                   | 5              | 2                     | 18                  |
| 8                               | 1             | 55                    | 55                  | 55                   | 3              | 0                     | 18                  |
| 9                               | 4             | 22                    | 67                  | 40                   | 1              | -                     | -                   |
| 10                              | 3             | 19                    | 56                  | 40                   | 5              | 0                     | 17                  |
| 11                              | 6             | 19                    | 56                  | 34                   | 9              | 1                     | 13                  |
| 12                              | 4             | 19                    | 70                  | 41                   | 4              | 0                     | 13                  |
| 13                              | 1             | 36                    | 36                  | 36                   | 5              | 7                     | 15                  |
| 14                              | 3             | 22                    | 64                  | 39                   | 1              | 8                     | 8                   |
| 15                              | 3             | 22                    | 48                  | 31                   | 10             | 0                     | 16                  |
| 16                              | 3             | 22                    | 60                  | 47                   | 8              | 1                     | 18                  |
| 17                              | 3             | 20                    | 75                  | 48                   | 2              | 1                     | 17                  |
| 18                              | 2             | 36                    | 46                  | 41                   | 3              | 1                     | 17                  |
| 19                              | 6             | 20                    | 63                  | 38                   | 3              | 2                     | 9                   |
| 20                              | 2             | 52                    | 60                  | 56                   | 7              | 1                     | 18                  |
| 21                              | 4             | 22                    | 75                  | 55                   | 4              | 1                     | 18                  |
| 22                              | 2             | 40                    | 49                  | 45                   | 3              | 1                     | 17                  |
| 23                              | 4             | 19                    | 78                  | 42                   | 9              | 2                     | 13                  |
| 24                              | 3             | 20                    | 41                  | 32                   | 6              | 1                     | 18                  |
| 25                              | 3             | 19                    | 67                  | 42                   | 5              | 3                     | 15                  |
| 26                              | 7             | 0                     | 61                  | 35                   | 8              | 4                     | 19                  |
| 27                              | 5             | 26                    | 72                  | 43                   | 1              | 10                    | 10                  |
| 28                              | 7             | 19                    | 83                  | 40                   | 7              | 3                     | 16                  |
| 29                              | 4             | 18                    | 58                  | 34                   | 2              | 1                     | 8                   |
| 30                              | 2             | 21                    | 47                  | 34                   | 1              | 18                    | 18                  |

The smallest household had three members and the largest had fifteen members.

#### *Adults*

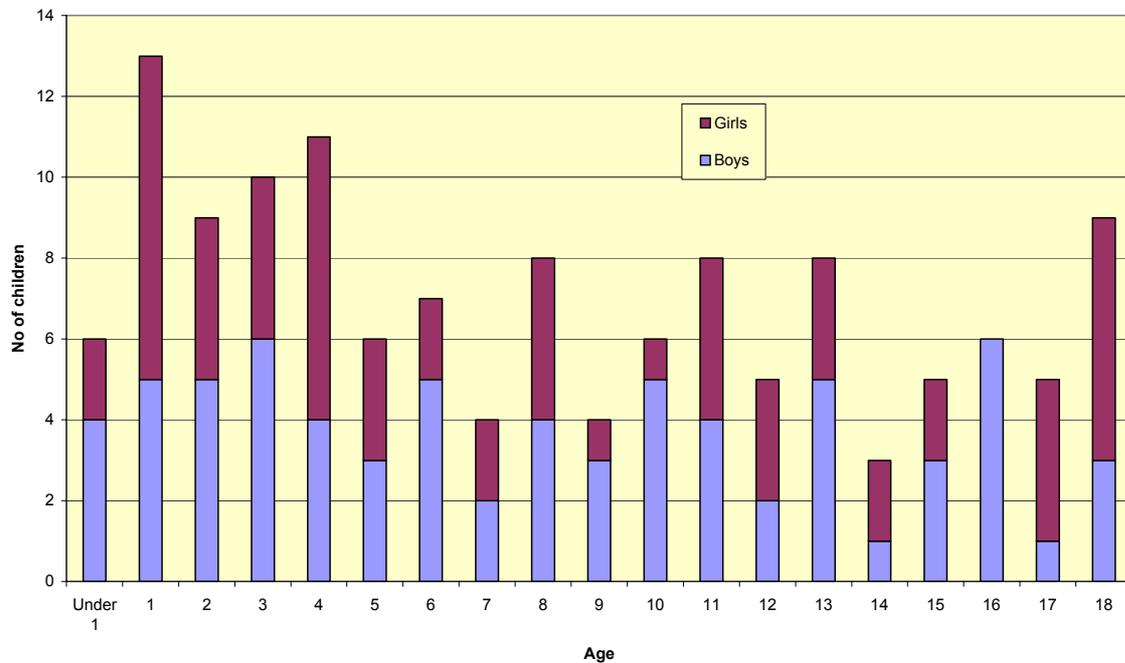
The average age of the adult population was 39 yrs old, the youngest adult member being 18 yrs old and the oldest 89 yrs old. There were female adults in all thirty households, but only eight female-headed households in the sense that there were not any male adults in these households.

The majority of the adult population (N=62) did not have partners. Eleven households had no couples living there. Also half of the households (N=15) had at least one member that was not a permanent resident but visited them usually less than once a month.

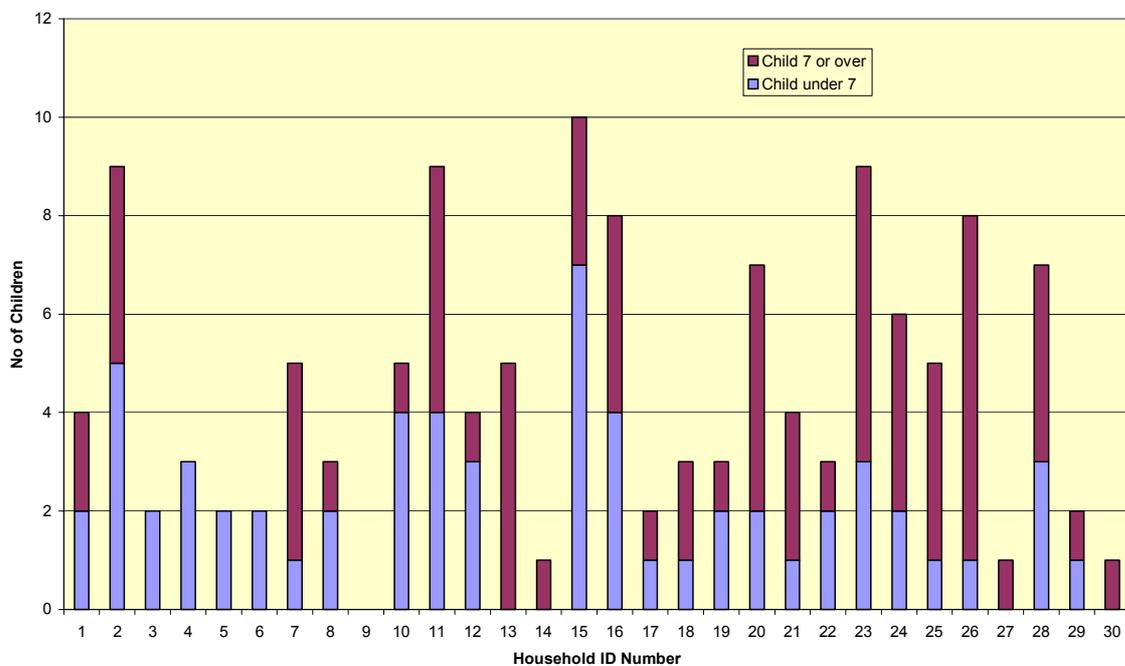
## Children

All of the households had children: four households had only one child whilst nine households had more than five children. The following chart shows the age distribution and their sex:

**Chart 4.1: Age distribution and sex of children**



**Chart 4.2: Distribution of children aged under 7 across the study households**



Children ranged in age from a month to 18 years. The mean age for boys was 8.25 and for girls 8.1. The presence of children under 7 in a household is crucial for determining eligibility

to Child Support Grant. From the chart 4.2 we can see that all but 5 households had at least one child under 7.

The biological mothers of five of the children and the biological fathers of 26 of the children were no longer alive. However, 38 children did not live with their biological mother and even more of them (N= 62) did not live with their biological father. The most common reason for the absence of the biological mother from the household had to do with the mother's work (working away or seeking employment elsewhere). The most common reason for the absence of the biological father from the household had to do with the father not being involved in the child's upbringing. The primary caregiver was the 'father' for 48 children, the 'mother' for 43 children and 'other' for 42 children. 'Others' included grandparents.

### **Children and Schooling**

There were 34 boys and 30 girls who went to school; the average educational grade was grade 4. Thirty-four children received food at school compared to 27 who did not. Twelve children received food at school twice a week, five thrice a week and four children received food 4-5 days a week. Two of the school-going children were working 4 hours a week for themselves. The majority of children walked to school (N=39) taking them an average of approximately 17 minutes to get there during the summer or winter period.

Ten girls and three boys in eight households had stopped schooling, the most common reason being the lack of money to pay for school fees and uniform (N= 7), followed by reasons related to child pregnancy (N=3).

### **Schooling and educational status of adult household members**

In eleven households there were thirteen adults, six males and seven females aged 19 to 24, who were going to school. Their grade levels ranged from six to eleven with most school going adults attending the 10<sup>th</sup> and/or 11<sup>th</sup> grade. Only four of these adults received any food at school three to five times per week. Only one of these adults was working as self-employed for four hours a week. Only one school going adult used public transport, the rest walked to school. Travelling to school could take up to 2 hours for some people.

In all but one household there was at least one adult with some type of education and in more than half of the households (N= 18) there was at least one member who had finished high school.

### **Employment**

A high degree of unemployment was reported amongst the thirty households. This is consonant with evidence that the Eastern Cape has the highest rates of unemployment in the whole country.

The majority of the adult household members was unemployed. Sixty-three adults were unemployed in comparison to thirty-nine who were engaged in some form of informal, episodic or temporary employment. All but three households had adults who were unemployed at the time of the survey.

The reasons cited for job loss varied from ‘downsizing’ (N=6) to ‘disciplinary dismissal’ (N=3) and ‘disability’ (N=2). The employment patterns of those who were employed was either informal, episodic or temporary. Few of those who were doing some form of paid work thus made enough money or worked steadily throughout the year. In particular, the majority (N=26) were self-employed selling dagga, wood, thatching grass and/or mud bricks. The majority of the self-employed (N=20) had a poor cash flow over the previous six months; sixty-two percent of self-employed earned a monthly amount of only R50 to R100. The following

*“The informant sells bunch of wood at R12 per bunch. Gets about three customers per week. When it rains the children are sick and she does not go to the forest so she loses on business. Mud bricks only done during dry season, so its seasonal work. She thinks she makes about 100 bricks through the entire season which sell for 90 cents per brick”* Interview Notes Household 4

Only eight adults worked full-time; the rest of the employed adults worked either part-time (N=3) or were in temporary employment (N=2). Ten of these adults worked in the informal sector and only one worked in the private sector. Only nine employed adults recorded their monthly earnings which ranged from R200 to R448.

The high degree of unemployment is indicative of the absence of opportunities for making and sustaining an income in the households of Mount Frere and the Eastern Cape more generally. This makes households very significantly reliant on income derived from sources other than direct employment such as remittances and state transfers or social security grants.

### **Prevalence of Chronic Illness**

Nineteen households reported incidence of severe chronic illness in the past year. This illness affected 15 adults and 22 children. In eleven households, illness symptoms were indicative of HIV although only appropriate medical tests could prove this absolutely. The table 4.2 gives the illnesses reported. Those shown in yellow were judged to have member(s) with illnesses which *might* be indicative of HIV/AIDS.

The duration of the chronic illness reported was between six months and 10 years. For the majority of the adults illness had lasted between one and four years.

Respondents were asked to report in chronological order the sources from which medical help was sought for chronic illness in the household. Initially, ten of the 15 ill adults had sought medical help from a doctor in a public health facility, two from a doctor in a private health facility, and one from a nurse in a public health facility. Three ill adults sought additional medical help from a doctor in a private health facility, one from a nurse in a public health facility and two from a traditional healer. Finally, four ill members sought further help from a traditional healer. Nobody sought help from either nurses in a private health facility, medical assistants (public/private), other medical professionals and/or community health workers. On average ill members spent approximately 2 years on medication.

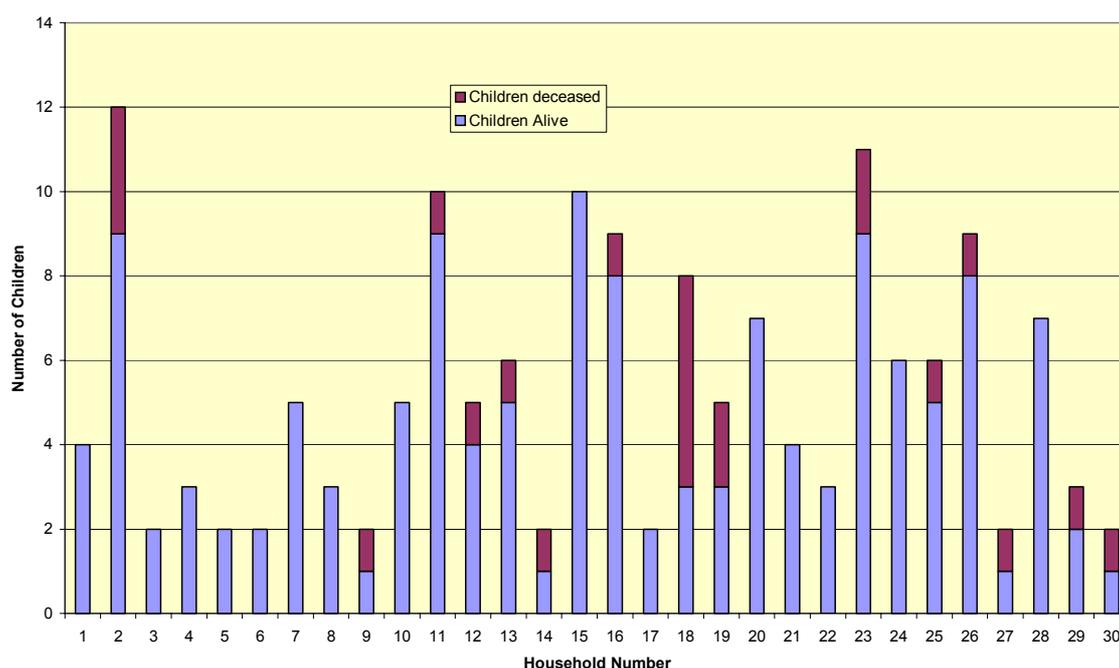
**Table 4.2: It shows the identification number of HHs with one ore more ill members and the symptoms of their illness (note that HH ids in yellow were judged to have member(s) with HIV indicative illnesses.**

| HHID | Symptoms   |
|------|--|
| 01   | Loss of weight, loss of appetite, chronic chest pain (1 <sup>st</sup> person)<br>Loss of weight, loss of appetite, chronic chest pain (2 <sup>nd</sup> person) |
| 02   | Tuberculosis   |
| 04   | Chronic heart condition  |
| 07   | Epilepsy, high blood pressure, diabetes  |
| 09   | Chronic coughing, tight chest,   |
| 11   | Chronic coughing, diarrhoea, body swelling   |
| 12   | Cerebral palsy, nausea & vomiting, fits  |
| 13   | Lung infection, severe body pains,   |
| 14   | Tuberculosis   |
| 17   | Malnutrition   |
| 18   | Tight chest, body swelling, severe headaches   |
| 19   | Tuberculosis   |
| 20   | Malnutrition, tight chest, diarrhoea,  |
| 21   | Severe burns   |
| 22   | Epilepsy   |
| 24   | Tuberculosis   |
| 27   | Chicken pox, diarrhoea, nausea and vomiting  |
| 29   | Tuberculosis, shortness of breath (1 <sup>st</sup> person)<br>Tuberculosis, malnutrition (2 <sup>nd</sup> person)  |
| 30   | Chronic chest pain, shortness of breath, severe body pains.  |

### Recent death within the household

Twenty-three households reported at least one deceased member; in nine of these households all the deceased members were children. There were twenty three deceased children reported in 15 households. Of the fifteen children where the sex was known/disclosed ten were boys, five were girls. :

**Chart 4.3: Children in households**



The chart 4.3 depicts the children in each household and shows which households had deceased children.

The ages of deceased children ranged from a month to 12 years as is illustrated by the table below:

**Table 4.3: Age distribution of Deceased Children**

|               | No of Children |
|---------------|----------------|
| Not known     | 4              |
| under 6m      | 6              |
| 6m up to 1 yr | 7              |
| 1             | 3              |
| 2             | 1              |
| 3             | 1              |
| 12            | 1              |

There causes of death were as follows:

**Table 4.4 : Causes of death of Deceased Children**

| Cause of Death | N  |
|----------------|----|
| Malnutrition   | 7  |
| Diarrhoea      | 3  |
| Body swelling  | 2  |
| Gastro         | 1  |
| Vomiting       | 2  |
| Stillborn      | 3  |
| Unknown        | 3  |
| Other          | 2  |
| Total          | 23 |

There were sixteen deceased adults reported of whom eleven were men and five were women. Not all the ages were disclosed or known to the respondents. Of the six cases where the age was disclosed, one was aged 89 the others below pension age – two in their twenties, two in their thirties and one aged 40.

### **Household Expenses and Assets**

*“The only chair in the house is a school chair. The table is also a school table. An empty bottle crate is used as a second chair. There is one single bed in the house. A pile of ragged blankets is lying on the corner as there is no wardrobe. The blankets are used by child for sleeping” Interviewer Notes Household 11*

### *Food*

Almost all households had to buy most of their food. Twelve households complemented their food resources by home production and a further three received additional food by means of bartering or donations.

The majority of the households (N=23) bought food monthly spending an average of R279.35. A household had on average six food items in stock. All households listed items they could not afford to buy. Also an average household had bought 2 non-food items in the previous three months spending R66.61 per month

Out of 36 possible food items asked about, the most items found in a household were thirteen. All but one household had cereals but there was no household with fruits at the time of the interview. Other food items found in the households included: (a) other foods such as tea, coffee etc. (83% of households), (b) fats and oils (47%), (c) animal products (30%), (d) milk products (20%), (e) legumes (53%) and (f) other vegetables (30%).

### *Possessions*

No household owned a telephone, in line with evidence on low rates of access to telecommunications. Nine households did own a radio. Almost all households had livestock (N=27), a bed (N=27), a table (N=27) and a stove (N=26). Almost half of the households owned land that they utilized (N=17), had a wardrobe (N=16), and an animal-driven plough (N=12). A minority of households owned land that they did not use (N=7). A respondent explains:

*“You need cows to do the initial turning of the soil (pre-planting phase) in preparation for planting. We don’t use land because we don’t have cows and we can’t afford to hire a tractor which costs about R200 per day depending on the area size”.*

Respondent Household 4

### *Sale of assets*

Over the last 12 months, 12 households had sold their livestock (four of them to cover educational expenses), one household had sold a bed and another had sold a wardrobe - again for educational expenses.

The presence of children was a significant factor in the realization of assets. Households that had sold at least one item tended to have more children eligible for social security grants, more children who were attending school, and more children cared for by a non parent. Also the higher the expenses incurred by children schooling the more likely it was that the household would sell one of its assets.

**Table 4.5: Differences between households that had sold their assets and those that had not**

|                                      | Not sold | Sold    |
|--------------------------------------|----------|---------|
| N of children                        | 3.13     | 6.00**  |
| N of children eligible for S/S grant | 1.44     | 2.93*   |
| N of children with non-parental care | .69      | 2.21*   |
| N of school-going children           | 1.13     | 2.43**  |
| Expenses for children schooling (R)  | 108.31   | 349.36* |

### *Housing*

Only one household was living in a house made of brick/concrete. The majority of households were housed in buildings made of mud (N= 28). Some had also tin (N= 12) and some ( N=10) had also used other materials.

As a source of drinking water, 16 households used a river/dam and 10 used a communal tap. Two households used rainwater, one used a borehole, and three households also stated their source of drinking water as ‘other’.

Twenty-six households did not use any kind of latrine and only three households used a pit latrine. As a source of fuel most households used cow dung (N=26), paraffin (N=23), and wood (N=28); no household had electricity or used solar power.

### *Educational Expenses*

Twenty-three households had annual expenses related to children and/or adults’ schooling. The highest school-related annual expense was for uniform (mean = R17.48 for adults; mean= R118.03 for children), followed by the annual school fees (mean= 9.71 for adults; mean = R27.98 for children). School expenses put considerable financial strain on the households. In some cases the school children themselves helped out with the costs:

*“The 3 kids listed on the list of self-employed are school kids. The trio goes to the forest over weekends when not in school. The first 2 are the children of the informant, the 3<sup>rd</sup> girl is her grandchild. The trio sells wood to pay for school fees and other necessities like soap to wash and school clothes, Vaseline, concert money, and pens. Because it is not culturally acceptable for boys to fetch wood, they do not perform this task thus miss out on generating income”* Interviewer Notes Household 11

The data, however, did not show a direct relationship between lack of educational participation and illness/death in a household.

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This description of the household circumstances of our sample provides further empirical evidence of severe impoverishment in the Eastern Cape. Households in this study had access to only basic foodstuffs and no household exceeded thirteen food products of a possible thirty-six food items. The evidence also suggests a process of asset liquidation occurring, with twelve households recording sale of their livestock in the interviews, with four households doing this in order to sustain educational expenditure.

### **Expenditure resulting from chronic illness and death**

#### *Chronic Illness*

There were significantly more unemployed adults in households which had members with chronic illness with symptoms consistent with HIV. This suggests a close correlation between illness symptomatic of HIV and unemployment as chronic illness, including those associated with HIV, gradually debilitates the functional capacities of household members.

Based on food purchases, households reporting no chronic illness bought greater amounts of food than those with chronic illness particularly chronic illness consistent with HIV infection.

In contrast to the amount spent on funerals, households seemed to have spent very little on medication costs for ill members.

### *Death*

Eleven out of fourteen households with deceased adults reported costs of funerals; in eight of these households the family paid for the funeral, sold its livestock to pay for it and/or took out a loan. The funerals of twelve of the deceased children did not incur any cost. Five households reported financial effects due to death of adults in the household; these effects included loss of income, funeral expenses and increased caring responsibilities.

The evidence from the study suggests that expenditure on funerals is a major cost in household expenditure with sale of livestock and/or loans being made to sustain funeral costs. It is interesting to note that funeral expenditure was directly correlated to the age of deceased – with older adults incurring greater funeral expenses than infants. This suggests significant costs for households.

### **The role of social security grants in alleviating poverty**

The social security grants which are investigated in this study are the Child Support Grant, the Old Age Grant, the Disability Grant, the Foster Care Grant, the Care Dependency Grant and the War Veterans Grant<sup>96</sup>. There is also a grant-in-aid which is distributed as a once off

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The eligibility criteria for the grants, which are all means- tested, are as follows

<sup>96</sup> **Old Age Grants** are paid to women who are 60 years of age and older, and to men who are 65 years of age and older.

**Disability Grants** are paid to people who are 18 years and older, who are disabled for six months and more who cannot support themselves because of the nature of their disability and other reasons.

**War Veterans Grants** are paid to people from the age of 60 years and older, who once served in the South African army during certain wars – the Anglo-Boer War (1899-1902), the Zulu uprising (1906), the First World War (1914 – 1918), the Second World War (1939 – 1945) or the Korean War (1950 – 1953), and who are unable to maintain themselves due to physical and/or mental disability.

To qualify for this grant, which is slightly more than the old age pension, proof must be provided that he was in the army during one of these wars.

**A Child Support Grant** is given to a primary caregiver who cares for a child or children (up to a maximum of 6 children) who are under the age of seven. The caregiver must not be in receipt of income in respect of the child/children. The caregiver can be the mother, father, grandparent, relative, friend or other, of the child or children. The requirements for receipt are a 13 digit identity number in respect of the children. Bar-coded ID document of caregiver. Proof of income or where the caregiver is unemployed an affidavit to this effect.

The **Care Dependency Grant** is for children who are severely disabled who need special care. Their needs must be proved by a medical doctor (for example the District Surgeon) in a government hospital. Parents or foster parents may apply for this.

emergency payment but is of nominal value and infrequently made available and is thus not considered as part of this study.

### ***Eligibility and uptake of grants***

The interview process yielded information which enabled the researcher to make an informed assessment of eligibility to the various grants based on the eligibility criteria detailed above. The following analysis is based on this assessment.

Although all thirty households contained members who were eligible for a social security grant, only sixteen households actually received any kind of social security grant.

The majority of households who were eligible for Old Age Grants were claiming them (N claiming N=13 eligible N=15) and half of the households with members eligible for a Disability Grant were receiving it (claiming N=2 eligible N=4). Among the fifteen beneficiaries of the Old Age Grant, eleven applied for it at a community point, two at Ntabankulu, one at Sipetu hospital and one at Umtata. To get to an application point, eight adults paid nothing and one paid R80; the rest could not remember. Thirteen of the applicants had an ID book at the time of their application but only one had some proof of income; also one provided some other document. Thirteen adults received their Old Age Grant monthly and only one received it every two months. Seven adults used the community as their collection point and five used the bank; only one person used the Mt Frere welfare office. The average travelling cost for collecting the Old Age Grant was R23. Eleven adults collected their Old Age Grant by themselves and three used family members.

However, the take up rate for social security grants targeting children was very low. In particular the take up rate for the Child Support Grant was only seven percent. There were only four children for whom the grant was received out of a potentially eligible population of 54.

Eleven applications were actually made for the Child Support Grant – most of them at a community point - at an average travelling cost of R19. For nine of these applications a 'Road to Health' Card was supplied but for only one application was a birth certificate available; another application presented another type of certificate. The grant was in payment in respect of four children across the thirty households. Two children were in one household; the other two were in separate households. The CSG was received monthly for these children from the community collection point where a family member collected it without paying anything for getting there. Three of the children who were not eligible for the Child Support Grant were

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**Foster Child Grant.** This is for children who are placed in the care of a person who is not their parent, such as the grandparent. This is done through a court case. You will have to go through the Means Test (see 4) to qualify for this grant.

**A Grant-in-aid** can be applied for by a person who already received a grant but needs full-time care from someone else. This is a very small extra amount of money over and above the grant or pension.

A person cannot have more than one grant at the same time (except for the grant-in-aid – see above).

A person will not receive a grant if they get total care in a state institution (such as state old age homes, prisons, psychiatric hospitals, or care and treatment centres) because they receive food and shelter.

(From: "You and Social Grants 2000", Department of Welfare, Pretoria)

working as self-employed selling wood, grass thatching and/or mud bricks; Their business cash flow was poor (R50-R100 per month).

Information about place, time period and cost of travelling to apply for the Disability Grant were not provided by either of the two recipients of that grant.

Of the seventeen households who contained members who fulfilled the eligibility criteria for the Foster Care Grant none of these were receiving it.

The low take up of social security grants by eligible applicants, with the notable exception of the Old Age Grant, is a major concern. It indicates the failure to obtain an income source which is a citizenship entitlement and which could have been used to financially sustain the household. The situation with the child support and Foster Care Grant is particularly telling: of the eleven applications which were made only one applicant had access to a birth certificate, a pre-condition for processing the recipients grant. This indicates a serious problem with the administration of the grants and an obstacle to the households receiving income support by the state via social security transfers such as the Child Support Grant. The fact that of seventeen households eligible for the Foster Care Grant, none of these were receiving any grant also points to fundamental information and administration flaws concerning this grant, although cultural factors related to foster care may play some part in the low take-up rate.

The receipt of grants by those who are eligible is dependant on effective administration of the grants. In view of the centrality of this issue, it was important, as part of this study, to undertake a detailed investigation of the claim processes and administrative infrastructure in the study area. This involved the researcher visiting the administrative offices involved with the processing of grant applications and conducting, where appropriate, depth interviews with the key actors.

The Chapter 5 discusses the findings of this part of the research study in order to provide a comprehensive picture of the failure in grant administration and its impact on impoverished households who may be eligible for such grants.

# Chapter 5 The Organization of Grant Administration in Mount Frere

The main provider of social services in Mount Frere is the provincial government via social security grants and poverty alleviation programs.

The main centres of social security administration are the national and provincial Departments of Social Development. Below the provincial department there are four tiers of administration of Social Development these are super-district, district, sub-district, and welfare committees. These tiers provide local access to the pension, child support, foster care, disability, care dependency, and war veterans grants as well as the various relief fund and poverty alleviation programs.

The national office, located in Pretoria, serves a policy-making and regulatory function, as does the provincial office located in Bisho, Eastern Cape.

At provincial government level, in addition to the Department of Social Development there are other key agencies which play a direct and active role in grant administration: the magistrates court, the provincial department of Health, the provincial department of Home Affairs, and local schools.

Local government is not well established, nor does it serve a significant welfare function. Instead it exists on the periphery of national and provincial programs as an advocate/facilitator. The local welfare office in Mount Frere is more likely to work with traditional leadership or village chiefs than local town councillors.

The super-district structure was created a few years ago to replace the regional office structure in an effort to bring decision-making processes closer to the point of service delivery. This super-district office structure is itself now being phased out.

The next level is the district. The district including Mount Frere is located in Mount Ayliff. This level contains the district manager and the social security data entry division for the district, that has its own autonomous budget and resources.

Sub-districts are semi-autonomous units that make up the district. Mount Frere is a sub-district. The sub-district is the lowest official arm of the welfare administrative structure and work closely with the district to enter collected data and initiate pay out. The sub-district manages over forty welfare committees or small groups of key figures in each administrative area which work on a voluntary basis to improve the outreach and administration of the grant uptake and pay-outs on the ground. While the welfare committees are unpaid, loosely supervised, and lacking official recognition from the welfare administration they serve an essential function for social security grant administration.

## **Problems with social security administration**

As we have indicated there are three intersecting departments involved in the administration of social security grants

### ***The Department of Social Development***

As we have indicated the provincial Department of Social Development has responsibility for receiving applications for grants, determining entitlement and arranging pay-out. It operates at very local level. There is an office in Mount Frere itself, from which some outreach work is undertaken.

One of the objectives of devolution is to bring the administration of social security closer to service delivery and so improve communication between different levels of government. Our research in Mount Frere has shown that this is not the case. Communication is hampered by a lack of phones, unreliable and irregular postal services and inadequate transport.

### ***The Department of Home Affairs***

In order for an eligible social security grant applicant to access a grant, an applicant is legally required by the government to produce various identification documentation. The Department of Home Affairs is primarily responsible for the production of such identity documents (ID). These documents include the Republic of South Africa ID book, the birth certificate, marriage certificate, and death certificate.

There are five levels of administration for Home Affairs and the most important are the service points in seven locations in and around Mount Frere, the district office located in Mount Frere, and the central office in Pretoria. The service points, the point of contact for applicants, are located in Qumbu, Mount Frere, Tabankulu, Mount Ayliff, Maluti, Mount Fletcher and Umzimkulu. These offices serve as intake points for all document applications.

Depending on whether there is a computer in the local office, the marriage certificate, abridged birth certificate, and death certificate are produced on site and the applicant walks out with the document the same day a complete application is produced.

The ID book application is however only administratively processed at the service point but is then forwarded to the central office in Pretoria where the books are produced. The ID books are then sent back to the district office for distribution to the service points. Also, because there are no functional computers in the Mount Frere district the three documents which can be produced immediately are sent to be processed at the Kokstad office which is the closest office with adequate processing resources.

The regional office, located in Umtata, is the site of the regional representative who serves an indirect supervisory role for the Mount Frere district and other districts in the Eastern Cape Province. The regional director is located in King Williams Town, a neighbour town of the Eastern Cape provincial government central site in Bisho.

In contrast to the devolved Social Development Department, the Department of Home Affairs is highly centralized. A review of the function of the Department of Home Affairs uncovers the same resource deficits as the Mount Frere welfare administrative structure.

There are inadequate resources such as staff, telecommunications, transport, and utility infrastructure to communicate effectively with the various branches of the department.

The lack of reliable electricity to support the computers in the Mount Frere district offices severely disrupts data inputting<sup>97</sup>

Currently, the Department of Home Affairs service points collect the ID applications and deliver them to the Mount Frere district office. They are then taken to Kokstad twice a month for computer entry and processing and then returned to the Mount Frere district office which distributes the documents to the seven service points.

This entire process can take up to a month and is heavily reliant upon the condition of the roads and transport for the journey to and from Kokstad and to and from the various service points.

The overarching problem with the role of Home Affairs in the administration of social security grants is the responsive versus proactive approach of the department for application intake. One of the legacies of Apartheid is that since the Transkei region was a Homeland/Bantustan independent of the Republic of South Africa (RSA) until 1994, citizens of the region are less likely to have official RSA documentation such as birth, death, or marriage certificates or ID books. This demands a more aggressive and efficient approach to providing the area residents with the required documentation to benefit from the constitutionally endowed social security entitlements of citizenship.

### ***The Department of Health***

The Health department is the third leg of the social security administrative circle. There are two divisions of this department involved in the securing of grants: the maternity function and the district surgeon and superior regional medical officer.

Due to the largely rural service area, the birthing function is *de facto* decentralized. The maternity ward of the two main area hospitals, Mary Therese and Sipeku, delivers a minority of the babies born in the area because the majority of Mount Frere residents live far from these two facilities and there are no ambulances or regular/reliable medical transport.

There are roughly seventeen clinics and in the health district which includes Mount Frere. Five of the Mount Frere clinics are in permanent structures and the other five are in temporary structures, the other seven clinics service the Mount Ayliff area. All clinics do deliveries, and eight of the ten in Mount Frere are 24-hour facilities.

The third element is the traditional birth attendants (TBAs) who are trained by the district and located in the villages which comprise Mount Frere. The TBAs are involved in home births to facilitate a successful birthing process. The TBAs and clinics are involved with the majority of Mount Frere births. There is a maternal and child health coordinator who oversees all of the sub-divisions of maternal health, minds the services, and works closely with welfare to ensure that the quality and range of services meets the needs of the community. The key function of this division of the health department is to conduct required immunizations and issue the Road to Health Card (RTHC) to all newborn children. This card is a pre-requisite document for Home Affairs to process a birth certificate for a child. And the birth certificate, in turn, is a pre-requisite for obtaining access to the social security grants.

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<sup>97</sup> SABC television documentary

The district surgeon and regional medical officer of the provincial health department also play a key role in the administration of social security grants. Applicants for Disability Grants are given a form at the local Welfare department which the district surgeon must fill out to determine whether the applicant is eligible for the grant based on the illness which he or she claims to have. The regional medical officer, located in Kokstad, looks at the recommendation of the district surgeon to verify the diagnosis (without the presence of the patient). He serves this function for a number of health districts in the former Transkei area. The applicant is rejected or granted the Disability Grant on the basis of the means test, applied at each level of the welfare administrative infrastructure, and the medical appraisal. The process is facilitated on behalf of disabled children by the hospital's nurses, social workers, and then forwarded to the district surgeon to undergo the same process as Disability Grants.

There are a number of criticisms which can be levelled at the role of district surgeon/medical officer function. The regional medical officer function is inefficient because it creates another level of bureaucracy and adds backlog potential because of the sheer volume of medical appraisals which demand review. With the upsurge of medical concerns such as TB, HIV/AIDS, and severe malnutrition and the pervasive poverty and under-development of the area, the need for optimal efficiency to process these applications is clear. Furthermore, the fact that the regional medical officer does not actually see patients calls into question the logic of this added level of bureaucracy. There was a recent court case which challenged this function, but the ramifications are undetermined<sup>98</sup>.

The line management functions of the district surgeons and regional medical officers lie with the Department of Health. However they carry out functions more or less exclusively for the Department of Social Development. This situation has the potential for confusing the lines of accountability.

Having discussed the structural context, we will now look in a more detailed way at the administrative arrangements which have the lowest take up rates amongst our study population. That is the Disability Grant, the Foster Care Grant and the Child Support Grant.

### **Disability Grant**

The Disability Grant which gives grantees R570 per month is an important poverty alleviation measure for residents of the area, particularly as there is such a high prevalence of chronic illness.

Dr. Ngcwabe, the district surgeon, explained,

*"people here live in poverty. The Disability Grant for one person is not only feeding that person they are feeding sometimes 7 other people. It is not for that person only, it is for the whole family. They are all depending on that money"* (Ngcwabe, interview transcript, 6/8/01).

To illustrate the claim process let us look at an example. Take the case of a 40 year old HIV positive man who is both a father and grandfather. On becoming chronically sick he might, after exhausting the possibilities of traditional medicine, visit a non-traditional medical

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<sup>98</sup> See *Ngzuma and Others v. Permanent Secretary of Welfare, Eastern Cape and Another*.

practitioner. This medical doctor, if convinced of the man's disability, sends a letter of referral to the local Welfare Office recommending that the district surgeon formally evaluate him. The chronically sick man will at the same time obtain an application form from the local Social Development Department either by going into the office or from the welfare committee representative in his village. The man will then attend the drop-in clinic of the district surgeon or make an appointment. The district surgeon is located in the town centre a block from the magistrate, welfare, and home affairs offices. The man will give the district surgeon the form and he will evaluate the patient based on the requirements specified on the form and a list of qualifying ailments which is provided by the Department of Social Development. HIV positive status for instance only qualifies if the infection prevents the applicant from being employed and actively engaged in the procurement of livelihood and care. The National Department of Social Development defines a disability as:

*"A disability is a long-term or recurring physical or mental impairment which substantially limits prospects of entry into, or advancement in, employment"*<sup>99</sup>

Therefore, a large portion of the HIV positive community is not eligible. This demarcation does not take into account the impact of social stigma, discrimination, and familial care-taking responsibilities for HIV positive persons who are physically able to work.

The district surgeon forwards his evaluation directly and confidentially to the welfare office. Then, if the evaluation states that the man qualifies on medical grounds, a social security clerk will proceed with the application process by requiring the applicant to produce and photocopy the RSA ID book, birth certificate (if he is applying on behalf of an HIV positive child), proof of income, marriage certificate if married and proof of partner income if married. Once complete the application will be forwarded to the regional medical officer in Kokstad and after he completes his second evaluation of the medical condition he will forward the application back to the Mount Frere welfare office for final processing.

This process can take from one to six months. If successful, the means test will be applied and the application forwarded on to the district office in Mount Ayliff. In Mount Ayliff it will be entered into the nationally linked intake system to initiate pay out. Time delays are frequent:

According to Ms. Sompeta, the district social security supervisor,

*"there is a process of them [the applications] going to the regional medical officer in Mount Ayliff . . . and he is looking at applications from nine districts . . . so it takes a very long time"* (Sompeta, interview transcript, 15/11/01).

Through interviews with the welfare officials at the Mount Frere sub-district office, it is apparent that although the demand for the Disability Grant is high given the prevalence of chronic illness and low income in the Mount Frere area, it is one of the most difficult grants to access even if the necessary documents are available.

The regional medical officer structure which acts as a second mediator between the application and approval adds additional time and no value to the application process. The District Surgeon reviews the applicant to verify that the ailment claimed is legitimate and

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<sup>99</sup> The Tiny Little Book That Tackles Great Big Issues: A guide to social security in South Africa, Van Schaik Publishers, Pretoria, 2001, p. 73.

eligible for the grant. The Regional Medical Officer then reviews the review based on no additional evidence and without the applicant present. Furthermore, due to the high volume of applications from the regional medical officer's vast service area, this mediation can add months to the application process.

### **Foster Care Grant**

One ramification of a rapidly depleting middle age population through HIV/AIDS related deaths is a growth in the number of orphaned children. The transmission mechanism of HIV/AIDS often leads to a high likelihood of dual parent infection and contemporary deaths. If both parents do not die in close proximity then there is typically a period of inadequate child care because the living parent is usually infected and burdened with caring for themselves and other family members in a compromised state. The cost of care for an HIV positive household member is taxing on the household for an extended period of time from the inception of costly medical care to the funeral.

The toll of the epidemic is taxing all families as there is a high likelihood that there is at least one household member affected - therefore the absorption of these children into extended family networks is not occurring because there is no more capacity within the networks. Nonetheless there are a rising number of care arrangements being performed for orphaned children by extended family, neighbours, church affiliates, and community members. The Foster Care Grant is designed to provide financial assistance to such caregivers. Thus, while theoretically the demand for Foster Care Grant should be increasing, it is evident from the statistics that Mount Frere residents are not gaining access to this grant.

One of the issues is the overlapping conditions of entitlement between the Child Support Grant and the Foster Care Grant. The former is payable in respect of any child up to the age of seven whose family income is below the requisite income level, Foster Care Grant is as we have shown payable to orphaned children. Thus either (but not both) are payable in respect of an orphaned under 7 year old. It is always to the advantage of the family to claim the Foster Care Grant as it is payable at a much higher rate (approximately 2.5 times the rate of the CSG) and is payable until children reach the age of 18 or 21 (if still in school). The CSG while itself not well utilised in the Mount Frere area is, according to local officials, used more than the FCG even in cases where the latter would be more appropriate.

To explain the application process let us take an orphaned child whose grandmother becomes the care giver.

The applicant would present herself to the local social work office. During her first meeting with a social worker she would discuss the nature of the care-giving arrangement and subsequently the social worker would complete a home visit and write a report about the nature of the household. The social worker would also give the applicant a form to be filled out by the child's school if the child was of school going age stating that the child was in fact in and attending school according to the school register. From this point the social worker acts as the applicant's advocate and will assist the caregiver to secure the appropriate documents from Home Affairs such as an ID book, the child's birth certificate, and the parent's death certificate and/or an affidavit of the parent relinquishing rights to the child.

The caregiver will also be required to present proof of income for the means test. Meanwhile, the social worker will use the report to determine whether the care-giving arrangement merits

the Foster Care Grant, and if so, will contact the magistrate's office to arrange a court date for the requisite court order. The time gap between the date request and the actual hearing can be weeks or even months because the location of a hearing on the docket is completely dependent on the prosecutors and there is no priority given to time sensitivity or topical urgency. The actual hearing is very brief and usually successful. According to Mr. Dengana:

*"It is not a very long process. I do not know if any application that has taken more than 15 minutes. It can take longer than that if the application is opposed. In most cases these applications are not opposed. I have never had a case which has been opposed"* (Dengana, interview transcript, 14/8/01).

After all of the documents have been procured, including the court order, the application is then forwarded on to the social security clerks in the Mount Frere office who then follow the same procedure as with any other grant—they send it to the district office for data entry and insertion into the system for immediate pay out. The grant is then reviewed by the social workers every two years in order to assess the household environment of the child and the school status to ensure that the child is still in school, attending regularly, and performing well. The social workers explained:

*"We usually call the applicant about the review so that they can collect the necessary documents [like the school report] because maybe the requirements have changed and then we write a report on the current situation and we also need to make visits and they need to bring bank statements to see if they are managing the money correctly. And in between we are supposed to make supervisions because we need to visit the home, check if the child is well cared for, if they have clothes and everything, but because of the transport problem we don't do that"* (Social Workers, interview transcript, 14/8/01).

If the household environment or school record of the child is poor or inadequate then there is a recommendation that the Grant be discontinued, which is then forwarded to the district office level for a decision. The grant is automatically discontinued when the child reaches the age of eighteen. Extensions are handled on a case by case basis but as the grant is designed to provide educational opportunities the wholesale extension of the grant until the end of secondary education regardless of age is logical. Ms Setlaba explained:

*"I have been involved in the discussions about an amendment to the Social Security Act to be implemented in December 2001 which would extend the Foster Care Grant to age 21 or when the child finishes high school rather than to age 18 as it is currently. This change has been advocated because some children do not finish school by age 18 and the money is used for education related expenses and if it is discontinued before the child graduates then funding studies becomes very difficult and may be discontinued with the grant"* (Setlaba, interview transcript, 6/8/01).

The volume of applications for the Foster Care Grants, according to key administrative agents, is remarkably low especially given the demand factors we have outlined. When asked why he thought that the uptake for the Foster Care Grant was so low, the magistrate replied:

*“In some cases you find that the people in these areas are illiterate in the rural areas and some have never been to school. They do not know these procedures so I think maybe that can also be one factor that leads to this number being so few”* (Dengana, interview transcript, 14/8/01).

Administrative limitations also explain why the take up rate is low. As with all grants, the delays and frustrations of obtaining documentation such as the RSA ID book, death certificates, and the birth certificate are formidable. The birth certificate is particularly difficult to access in the case of foster care applicants because the Road To Health Card is often unknown and this document is a pre-requisite for the birth certificate. The alternative documents which will be accepted in the case of a late registration of birth also require documentation - a baptismal certificate or familial affidavit - that the foster care parent may not have.

In Mount Frere the key factors in grant administration are the court order process and the resource deficit of the social work section of the welfare department. This has a detrimental effect on the ability of social workers to perform their duties adequately. Due to under-staffing social workers are over-burdened by an unrealistic caseload which grows with each new case because they must be reviewed every two years for upwards of 18 years. The lack of computers, telephones, and regular transport are all factors which make the services which they are required to provide more time consuming and frustrating leading to further delays and backlog. Ms. Nkalane elucidates:

*“It takes long because we do not have transport to visit the homes in some remote areas because we only have one car that is used for social security pension pay outs and monthly they are going out 29 days of each month so we only get transport for professional services on that last week of the month and we are sharing that transport, all 6 social workers”* (Nkalane, interview transcript, 6/8/01).

### **Child Support Grant**

The Child Support Grant was introduced in 1998 to replace the highly racialised State Maintenance Grant following recommendations of the Lund Committee<sup>100</sup>. In order to broaden the uptake of this child directed support the grant was structured to provide a monthly payment for each child under the age of seven and this grant would be directed to the parent or primary caregiver of the child. The government declared that it would have like to see 3 million children receiving the grant by the year 2000. This target was not met. The Eastern Cape province has the highest number of CSGs in payment of any province. As Ms. Setlaba, super-district manager points out:

*“I am also proud that we have reached the most children here in the Eastern Cape of all the provinces. I understand that we are a poor province and that we may have the most children in need”* (Setlaba, interview transcript, 6/8/01).

However, it also has the largest *eligible* population. The take up rate (in the sense of recipients expressed as a percentage of the eligible population) is not known but is suspected to be low.

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<sup>100</sup> Report Of The Lund Committee On Child And Family Support August 1996

This can be largely attributed to the legacy of Apartheid and the expectation of inadequate service provision to former Transkei residents. According to Ms. Deketa, the head of department for the Eastern Cape Welfare Department:

*"It might be distrust of government that leads to difficulty in reaching out to eligible populations. Can I give you an example? I grew up in a rural community in the former Transkei homeland. My mother died recently and when people came to give offerings for the funeral I asked the mothers, 'have you applied for a CSG?' and they said 'No, we heard about the grant on the radio and from friends but we thought it was just another thing for the urban areas, but not for us in the rural areas. So maybe people are not used to having grants that they could apply for and don't think that the new programs are for them in rural communities'" (Deketa, interview transcript, 4/9/01).*

The process of obtaining a Child Support Grant is the same for all applicants regardless of relationship to the child, however, we will take the example of a mother of six children with two children under the age of seven. The first step is to visit the welfare office in Mount Frere on the intake day for the administrative area as advised by the welfare committee representative. This representative, if active, will inform potential applicants of the requirements for the grant application including obtaining a RTHC and birth certificate for the child and RSA ID book for the carer and a proof of income for the household based on the requirements set out in welfare department literature. The proof of income must prove that the carer is "not . . . in receipt of income in respect of the child/children."<sup>101</sup> The prospective applicant will produce copies of these documents to a social security clerk (there is one who works only on the CSG applications) who will complete the application form for the client. If the applicant does not have money to make photocopies there is a machine available in the office for use by clerks. The application will then be processed and approved at the sub-district level and the applications of successful candidates will be forwarded on to the district office to be processed by the data entry function and then the account will be activated for payout. As with all grants, unsuccessful applicants, those who do not fall into the means-tested income range, will be notified and told why did not get the grant.

Through aggressive campaigning in the communities hospitals, clinics, schools, and churches and targeted outreach, the Child Support Grant has been receiving a significant amount of attention relative to other grants since its introduction. In fact, there is a social worker stationed in the hospital one day per week for assistance in immediate placement of mothers onto the CSG.

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<sup>101</sup> You and Social Grants 2000, <<http://www.welfare.gov.za/Documents/archive/2000%20-1996/2000/ugrant.html>>

Ms. Mlandu, the sub-district manager, explained:

*"there is a social worker here who is providing services [once a week to the hospitals] but sometimes when there is a problem they phone to say what is wrong"* (Mlandu, interview transcript, 7/8/01).

However, these efforts have not resulted in uptake levels which reflect eligibility or need.

There are two categories of obstacles to accessing the Child Support Grant in Mount Frere—the administrative backlog and bureaucratic inefficiency of government departments (i.e. welfare, home affairs, health) and the situation of potential applicants.

The administrative problems are different in each department. However, there is a universal resource deficit which translates into under-staffing, a lack of adequate transportation, the over-extension and poor training of existing staff, and limited access to facilities such as telephones, computers, forms, office supplies, and fax machines. In addition, the RTHC can only be issued when the child is vaccinated. With the high volume of home births in remote locations and the lack of resources to support these areas with 24 hour clinics or traditional birth attendants, vaccination programmes become logistically difficult. Without the RTHC the mother cannot get a birth certificate which is itself necessary for application for the Child Support Grant.

The Department of Social Development itself has difficulty with the welfare committee representatives because due to their voluntary status they often fail to inform residents of the eligibility criteria and application requirements of the grants. Furthermore, the documents required by the Department of Social Development which are issued by the DHA, particularly the birth certificate, do not reflect the reality of household structure in the study area. For example, the surname on the birth certificate must be the same as the name on the RTHC and if the mother dies and the child is raised from birth by a grandmother or aunt or neighbour their name will not be replaced on the birth certificate.

Despite aggressive and regular campaigning about the grants there is still a widely held belief among potentially eligible grant recipients that the grant is not intended for them. This is a clear legacy of Apartheid when the welfare system in the Republic of South Africa was mainly accessible only by whites, Indians, and Coloureds with only limited provision by the Homeland governments.

## Chapter 6: The Experience of Poverty and Chronic Illness: The Respondents' Perspectives

This chapter details the experiences of the study households in relation to poverty, chronic illness and associated bereavement. The analysis draws heavily on the field notes taken by the researcher.

In order to deal meaningfully with the consequences of chronic illness associated with HIV/AIDS and to devise appropriate policy responses to alleviate poverty in rural areas such as Mount Frere, we need to understand how the experience of poverty and the cultural norms of every day life dictate the decisions households make over the meagre resources at their command.

We also need to understand how current policies and their implementation impact on families - sometimes with the unintended consequences of perpetuating or exacerbating rather than reducing poverty.

The thirty families who make up this study population have a wide range of inter-generational caring arrangements which are atypical of nuclear families. While reflecting traditional patterns of family structure, these arrangements are essential for sustaining family livelihoods. Without these fluid arrangements, child and elder care responsibilities could not be shared within and across families and the culture of reciprocity evident in food and other exchanges in times of crisis such as sudden family death, could not be as easily effected. The corollary of this, however, is that where families are dependent on another family member/relative who then fails to deliver financial or care support, this often leads to a household crisis.

This is illustrated by the example of household eleven. In this household the informant is the sole income earner who is financially responsible for nine children. She is the biological mother of four of the children. A further child of hers was admitted to hospital for malnutrition and subsequently died. Her partner, a contract worker, died two and half years ago and thus his financial support stopped. The extreme resultant poverty is reflected in the living conditions of the household. The only chair and table are from the school; there is a single bed for the entire house; and blankets, used by the children for sleeping, are piled on the floor as there is no wardrobe.

The informant relied on her mother (the children's grandmother) for support. The mother was a pensioner living in another part of the village and receiving a state Old Age Grant. She used a large part of her monthly groceries to support the family. Despite this support the informant was continually obliged to send the children to her mother to ask for food. As a result by the end of the month both families did not have anything to eat.

The informant's mother has now died resulting in the loss of the state pension as an income source. The income earner described the impact as such:

*“starvation is upon us. We do not have food, children go to bed without having eaten. Even last night we did not have supper. Children had to stop schooling”*

## **Income Failure**

The evidence which emerges from the interviews is repeated failure of income receipt, even from permanent employees such as mineworkers. In this context an alternative state source of guaranteed income seems essential if further spiralling impoverishment is to be avoided.

Many of the households in the Mt Frere area have male members who are absent working in the gold mines in Gauteng. The remittances they send to their families represent a very fragile source of support. There are frequent strikes when the miners do not get paid and remittances are therefore not sent. Even in our small sample this was evident. In other cases mineworkers have been retrenched causing permanent income failure as the following two cases illustrate.

First, the case of household 13 which consists of a widowed mother and her five children.

The husband, the family breadwinner, died in 1997. The husband was a mineworker who was retrenched and who at the time of his death had been out of work for a year. He came home with a retrenchment package of R7000. The money was depleted even before he died.

In the past four months the head of the household had started selling dagga in an endeavour to try to make ends meet. Selling dagga is illegal but she takes the risk because she knows of no other way to provide for her children. Each dagga stick costs her R100 which she sells for R300 and thus makes a profit of R200. It takes her anything from 2-3 weeks to sell her stock. During the time that she is away, her younger child goes to stay with his grandmother. The other children are left on their own. The older child is responsible for other siblings. Relatives, who stay in the same village are also requested to keep an eye on the children. When groceries run out, and the mother has not yet returned, then children rely on their relatives for food.

Second, the case of household 4 which comprises the informant, her husband, mother-in-law and three children. Her husband was working in Randfontein as a miner and was retrenched in 1998. He is now supported by his mother who is a pensioner. The miner received a lump sum on retirement but the informant does not have any decision making power over the retrenchment funds. She does not know how much he received as he kept all the money himself and bought building materials for their home. The informant provides for her family by selling bunches of wood at R12 a bunch for which she has three customers per week. However, when it rains or the children are sick, she does not go to the forest and thus cannot gather wood and make any money. During the dry season she also makes mud bricks. In the season she makes about 100 which she sells for 90c each.

This case has both a gender specific dimension in that the informant had no decision-making capacity over her husband's retrenchment package and a family wide dimension in that the family cannot be supported through seasonal self-employment.

Failed income is not, however restricted to remittances from mineworkers. Meagre, intermittent forms of self-employment heavily reliant on local weather patterns generate frequent income failure. The case of household 9 is common in the Mount Frere area. The informant sells wood for R10 a bunch. She takes over five hours to get to the forest. She is constantly suffering from physical exhaustion especially if she had been carrying a heavy wood bundle. The income generated from selling wood is very intermittent, particularly as her ability to secure her 'stock' is wholly dependent on the weather – when it rains she cannot gather any wood.

Self employment patterns in the sample households are characterized as episodic, provide minimal income and are almost always physically exhausting.

Particular types of government intervention have often also, inadvertently, resulted in income failure as is illustrated by the case of household number 20. This household consists of the informant, her husband and seven children.

The informant's husband used to work in the mines but was dismissed in 1983 because of partial deafness. He was treated in hospital for it but never regained his full sense of hearing. He was classified as disabled and was able to claim a Disability Grant in 1985. In March 2001 the Disability Grant was terminated. The official reason given was that there had been "changes in policies and regulations". He was advised to apply for an Old Age Grant and made a claim in June 2001. However, the Old Age Grant was only made available in December 2001. During the intervening six month period there was a complete breakdown in income and the family relied on a relative who was a miner and who sent R100 each month. The termination of the Disability Grant and delay in obtaining the Old Age Grant meant there was a drastic shortage of food. One child was sent to live with relatives whilst the youngest child was admitted for malnutrition and fell ill again as soon as he was discharged from hospital.

### **Reasons for non take-up of child support and other grants**

In Chapter 5 we showed that the key reasons for failure of households to receive grants to which they are entitled, relate to poor administration and lack of knowledge about grant entitlements on the part of eligible applicants. This is amply illustrated by the experiences of our study households.

Thus, for example, there was a 3 day outreach programme in respect of the Child Support Grant conducted jointly by the Department of Home Affairs and the Department of Social Development. The idea was that the DHA would facilitate the obtaining of the requisite birth certificates for the children while the DSD would accept applications for the Child Support Grant. In theory, this was an extremely useful way of bringing the CSG to the remoter parts of the community. In practice, there were considerable shortcomings in the service.

Thus, in the case of household 1 where Child Support Grant was not in payment, birth certificates for the children were obtained by the father on the second day of the outreach programme. However the outreach programme team wrapped up their work on the third day before the father, who had been waiting in very long queues, had the opportunity of applying for the CSG. The outreach team members said they needed to move on to the next point and would come back to complete the registration procedure by the end of the month. The parents were still waiting for their return at the time of the interview.

Another case (household 2) also illustrates the inadequacy of these outreach trips. When the outreach programme came to her village, the grandmother of 7 children (under 7) went to apply on behalf of all these grandchildren (for whom she was primary care giver). Because of the extremely long queues and her failing health she couldn't be seen by the team during their brief trip. For this reason the family are not receiving CSG to which they are entitled. This family was one in particularly dire financial circumstances.

In the case of household number three the mother (informant) was not obtaining the Child Support Grant for which she was eligible because she did not have the requisite ID documentation. When she attempted to make an application for her own ID documentation she was told to bring a relative to verify her identity. However she had no relatives who lived nearby and she could not afford to send for them.

In the final example here (household 17) an initiative taken by the grant applicant to overcome poor local administration arrangements has led to a great personal and financial burden for the older person concerned. In this household the 75 year old head of household is on an Old Age Grant. This key income source is supplemented by the two women of the family selling wood and working in other peoples' gardens. The head of household went to apply for the grant in Umtata (approximately two to three hours away by bus) as he had heard that the processing was much faster than in Mount Frere. He pretended that he was a resident of the Umtata jurisdiction in order to be served. Although he secured the right to access his pension in Umtata his initiatives have the consequence of him having to travel to Umtata to access his grant. Improved administrative procedures in Mount Frere would have obviated the perceived need for this course of action.

Despite the indications of administrative shortcomings detailed here, there is also evidence that great efforts are being made in the Mt Frere area to remedy the situation. The administrative authorities are pro-actively engaged in advocating for eligible grants by organizing take up campaigns and out reach work. There are, however, insufficient resources for the scale of the problem.

### **Social cost of school fees**

The imposition of annual school fees and uniform costs comes at a considerable social cost for the impoverished households in the study area. The families in general are not able to sustain expenditure beyond that required for livelihood (i.e. food items) and requirements for additional expenditure place enormous burdens not only on parents but on the school children themselves. Expenditure related to school attendance thus dramatically adds to the existing household poverty. Children from low income families attending school benefit from meal provision through the Primary School Nutrition Scheme (PSNP) but this benefit is undermined by the requirements to pay school fees and buy uniforms.

In household 11 the economic consequences of having to pay school fees are harsh. Although they are relatively old, two of the children, aged 13 and 11 respectively, are still in their first year of primary schooling (Grade 1), because they have been previously barred from attending school due to failure to pay school fees. They now have to sell wood to pay for their school fees and so be able to progress through the school system. The children have also been wearing the same school uniform for almost 3 yrs as the informant states that she cannot afford to buy them a uniform.

In the case of household 3, the child of the informant was removed from school because the mother could not afford the school fees. In addition to not having school fees the mother says she could not provide her daughter with a lunch box and that was a disgrace for the household.

These cases make an eloquent argument for eradicating school fees and introducing some form of school uniform grant as a means of alleviating the burden of poverty.

The positive benefits of attending schooling is shown in the case of household 5. In this household three of the five school children benefit from primary school feeding scheme/PSNP. However, in this household transport is a problem for the eldest school boy who has to walk for 2 hrs each day to get to school.

This household's account also illustrates the culture of reciprocity which exists in the school context. Each child pays 50c towards funeral costs when there has been a death in school of either a child or a teacher. This is also reported by household 17. R1 is paid when a school teacher has died as condolence to the bereaved family. In the context of the prevailing, severe impoverishment the sustaining of such a culture of reciprocity is not cheap.

### **Social and Financial Impact of illness and death**

The social and financial impact of illness in impoverished households are often intertwined and thus not easily separable. The following two examples illustrate how cultural norms significantly affect costs in the case of bereavement and burials, for example. In the case of deaths of grant holders, such as pensioners, the detrimental impact on the household of income loss is visible and significant.

We have seen in Chapter 4 that twenty three of the households had at least one deceased member and in nine of these households the deceased were children. The increase in deaths has a dramatic, draining consequence for the household's income as expenditure on funerals saps the present and future (through loans) household resources. Specific household and community customs governing the burial of the deceased also affect the erosion of resources. The important issues raised are illustrated by a number of the households affected by death—this section will concentrate on three illustrations.

One issue concerns the money that is spent as donations to the bereaved families. The giving of donations in cash or in kind is part of the culture of reciprocity or “gift-exchange” at the time of a death and ensures that there is a redistribution of resources for households affected by death to sustain themselves during the bereavement period through some form of collective assistance.

In the context of structural impoverishment and increased rate of death as a consequence of AIDS amongst other reason, this gift is unsustainable for individual families and the community as a whole. The respondent in household one mentioned, for example, that there had been five deaths in his section of the village and that the family had to borrow money in order to make donations to other families. This was considered compulsory as the other households had made donations to them during their own bereavement period.

The types of costs incurred are significant in that they are related to the status of the deceased with expenditure proportionate to age, and thus are greater for older people, senior household members and community leaders. The actual procedure is that each household in a particular section of the community donates a bar of soap, one candle and a box of matches (approx. R5) to the bereaved household. By custom a bereaved household lights candles 24 hours a day until the day of the funeral. On the day of the actual funeral the neighbouring households will donate another R5 – R10.

The actual funeral expenditure is also a significant drain on household resources. Funeral costs of R1050 are not atypical. Other costs are also incurred which are difficult to estimate. For example before the burial people from the community, church groups, relatives, visit the house. They are provided with tea and bread everyday and a substantial amount of money is thus used to buy tea, sugar, milk, bread or flour.

In some cases impoverishment resulted in the inability of households to afford funerals in a manner they would consider dignified and culturally appropriate. For example in one case (household 11) the 5<sup>th</sup> child of the informant (who supports a family of 14 of which 9 are her own children) died in Sepetu hospital of malnutrition.

This family is in extreme poverty and the child who had died was “temporarily” buried without ceremony two days after he died. It was explained to the interviewer that this was often done when a family is too poor to afford a ‘formal’ burial. It was expected then that when the family is able to afford the burial the body will be exhumed and the person given an appropriate burial. It is believed that if this is not done, the body will not rest peacefully and that the children growing up in that household would never be physically fit and healthy.

## Chapter 7 Conclusion and Recommendations

This exploratory study has assessed the relationship between state social security transfers and the capacity of a sample of rural poor households to sustain an income to meet their basic needs. Some of these households were affected by chronic illness, including illnesses which might be indicative of HIV/AIDS.

The study employed an innovative methodology which involved a depth interview conducted in accordance with an interview schedule which enabled the researcher to complete a detailed structured household questionnaire. Thus both qualitative and quantitative data were generated. The data collected on the household questionnaire has proved to be robust and capable of quantitative analysis. The sample of households however was purposive and small. This meant that only limited quantitative analysis could be meaningfully undertaken. Moreover, resource constraints also limited the quantitative exploration of the data. However, the interviews generated a wealth of qualitative information on the social security, income, education and health of the study households as well as their responses to conditions of severe impoverishment.

The review of the literature relating to other comparable studies indicated that the dominant coping strategies used by families in the aftermath of HIV/AIDS included reducing consumption or elimination of food items, decreasing meals to one meal at night time, selling assets, engaging in informal business activities, and borrowing from family or other sources. It also indicated that government intervention, including in the form of public transfers, was a significant means of supporting families undergoing a crisis precipitated by chronic illness related deaths such as those associated with HIV/AIDS. These findings are confirmed by evidence of households in the study sample.

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The residents of the Mount Frere area are living in extreme poverty or on the margins of it. They are extremely vulnerable to income failure and have no financial cushion against unexpected expenses. There is little work in the area, income comes from fragile self employment, intermittent remittances from absent family members and from social security grants paid to one member of the family but then shared widely across the extended family. Without the spectre of HIV/AIDS these families have a high probability of finding themselves unpredictably plunged into poverty. With the rate of HIV infection prevalent in the area, this probability becomes a certainty. HIV infection guarantees both income failure and increased expenditure both in life and in death.

The evidence from this study reinforces this general account. There were frequent reports of income failure. Household income often derived from some form of episodic self employment (in one case illegal employment), which brought meagre returns and were dependent on favourable weather conditions. Remittances were sent by family members or relatives often from mining work in Gauteng. These were also unreliable due to conflict and conditions in the labour market which prompted strikes and retrenchments. Grants such as the Old Age Grant provided a source of income not only for the older person but for the entire extended family. Thus where a recipient died or the entitlement was terminated, the entire household found

great difficulty in coping and were often driven into further and deeper poverty. Even the Disability Grant when in payment serves this more generalised income maintenance function rather than meeting the specific medical costs of the disabled person.

Not only are income streams liable to failure, but some categories of expenses place an intolerable additional burden on households already near destitution.

Some of these are predictable and flow from existing government policies. Education school fees and uniform costs are a stark example. In one example school children had to undertake work themselves in order to finance their school fees. Indeed for several previous years they had been excluded from receiving an education because their family could not afford the fees and uniforms.

Another unpredictable expense relates to death both of family and community members. This once relatively infrequent expense is now becoming ever more prevalent as the HIV/AIDS pandemic develops. In the first place there are the direct costs of the funeral and period of mourning borne by the affected household. However the culture of reciprocity means that some of the costs for funerals are communally shared and all households are obliged to make a donation towards the costs of the funerals of deceased neighbours in their immediate village area. Where a number of deaths occur this becomes an onerous burden and one family was even forced to take out a loan to pay the donations.

The existing system of state transfers should offer some protection against these income failures and burdensome expenses. However, the evidence is that take-up is low and the administrative infrastructure for the existing grant system is cumbersome, and under resourced both in financial and human capital terms.

The majority of families in the study area have children for whom the Child Support Grant or, in some cases, the Foster Care Grant, would be appropriate. However, the take up rate of these grants is very low. Often this is due to difficulties experienced by care givers in obtaining the requisite documentation in order to apply for these grants. The Department of Social Development and Home Affairs have inaugurated very worthwhile outreach programmes. However, these were too infrequent and under staffed to meet the huge demand.

The rules of entitlement for the Disability Grant, according to information given to local residents, do not permit the supporting of household members suffering from chronic illness – particularly that which is AIDS related.

## **Recommendations**

Our study was limited in scope and we cannot generalise the findings. However, if the experience of the study households is reflected more generally then there are clearly very serious concerns in a range of policy areas, discussed below, which merit further attention and further detailed research.

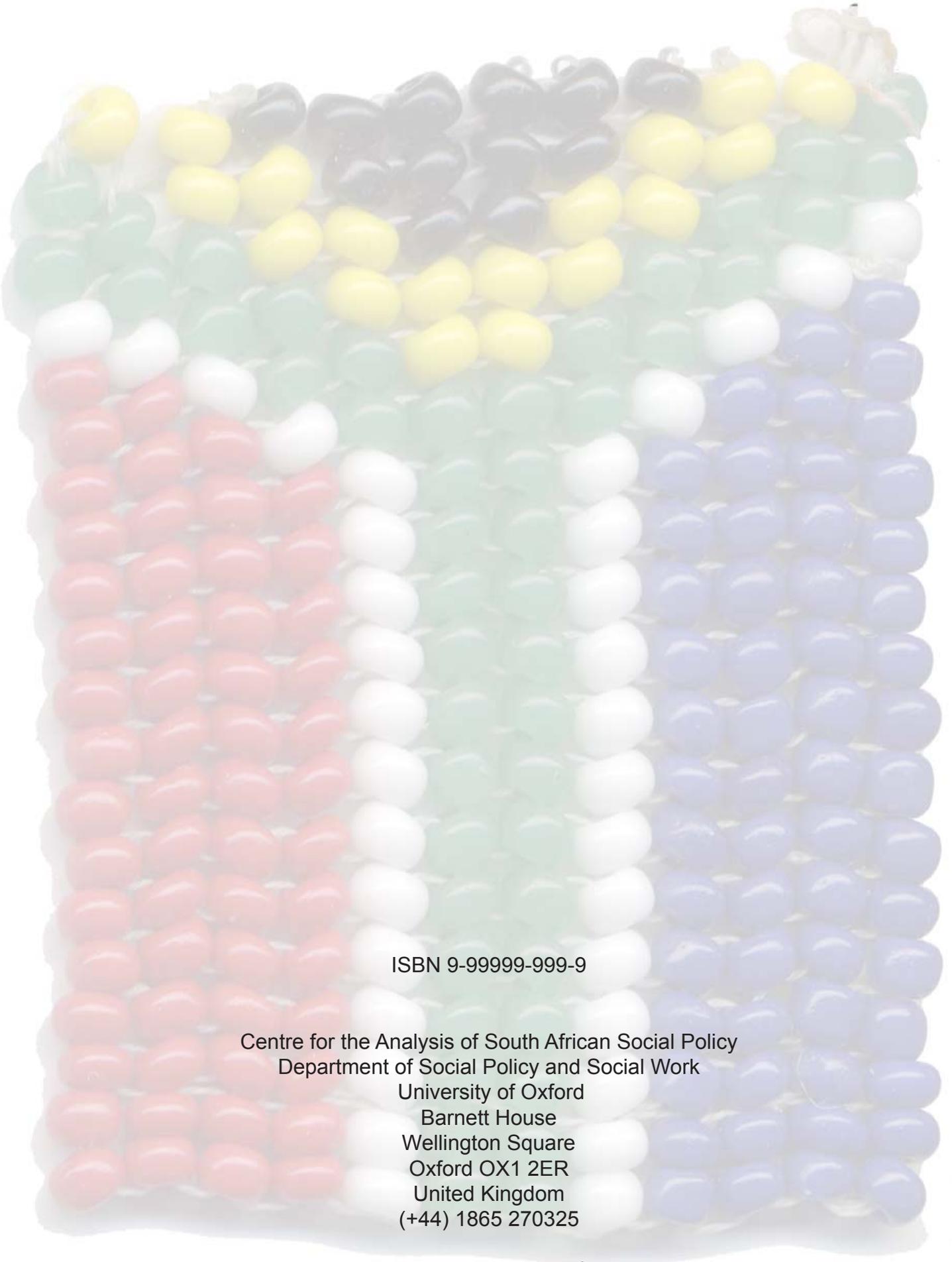
Persistent income failure which is exacerbated by illness and death of family members points to the need for a comprehensive state safety net. It cannot be right that older people and disabled people should be using their grants for this purpose.

All the children in our study population live in families of very low means. If this is typical of the Mt Frere district, state transfers for children need to be strengthened. The Child Support Grant seems a candidate for further reform. At present it does not serve the study households well. The administration is complex and it ceases when children reach the age of seven. Extending the Child Support Grant to all children under 18 and removing the means test would, we suspect, make a very significant impact on poverty in the area. The removal of the means test would have the effect of reducing the administrative burden and allowing existing resources to be deployed more effectively.

In any event, if our findings are indicative of wider problems with the current grant system, the grant delivery system has to be strengthened through increased resources – more well trained staff and delivery systems appropriate to rural areas - such as the outreach programmes - extended and strengthened. There also needs to be a simplification and reduction in the bureaucracy associated with administration of grants. Ideally the means test should be removed as an abundance of international evidence exists which demonstrate that the means test acts is not an effective mechanism for ensuring eligible recipients receive their entitlements to government social security.

Education is such an important weapon in the development of the country. There should be no impediments to this fundamental citizenship entitlement. School fees should thus be abolished. Consideration should urgently be given to provision of an annual school uniform grant. There are international precedents for such grants.

The increased mortality attendant on the AIDS pandemic suggests the need for government intervention specifically in supporting funeral costs. A death grant to provide for the funeral expenses in poor households would be an appropriate measure.



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