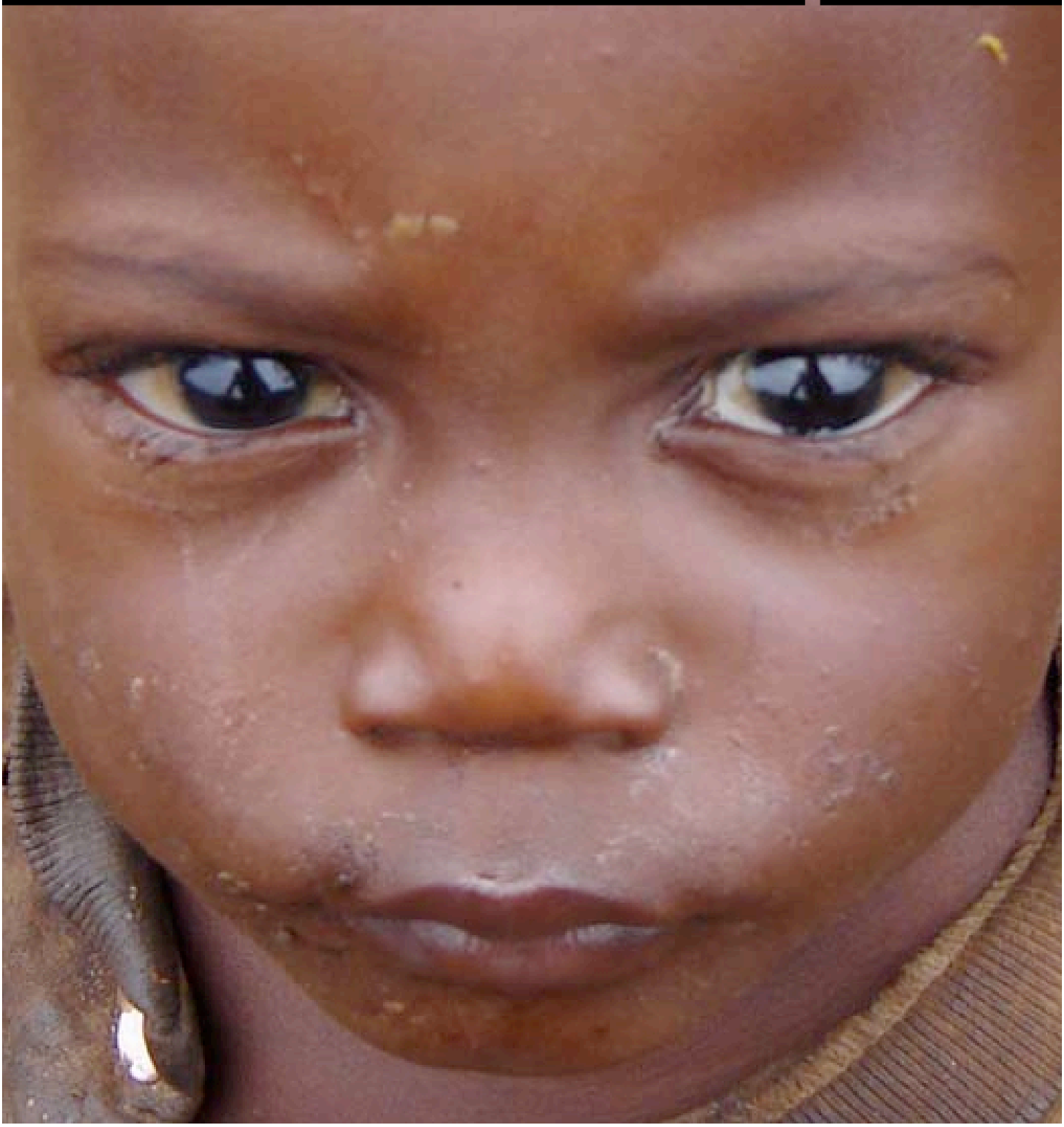
INNOCENT VICTIMS

The courageous struggle for survival of children infected with and affected by AIDS in Rakai district

MAHSP FIELD
PRACTICE REPORT
BY ALANNA JORDE
RRU 2004 COHORT



INNOCENT VICTIMS
The courageous struggle for survival of children
Infected with and affected by AIDS in Rakai district

By

ALANNA KATHLEEN JORDE

B.A., University of British Columbia, 1991

A Field Experience report, submitted in partial fulfilment of
the requirements for the degree of

MASTER OF ARTS

In

HUMAN SECURITY AND PEACEBUILDING

We accept this Field Report as conforming
to the required standard

_____
Hagaba Richard, Project Sponsor

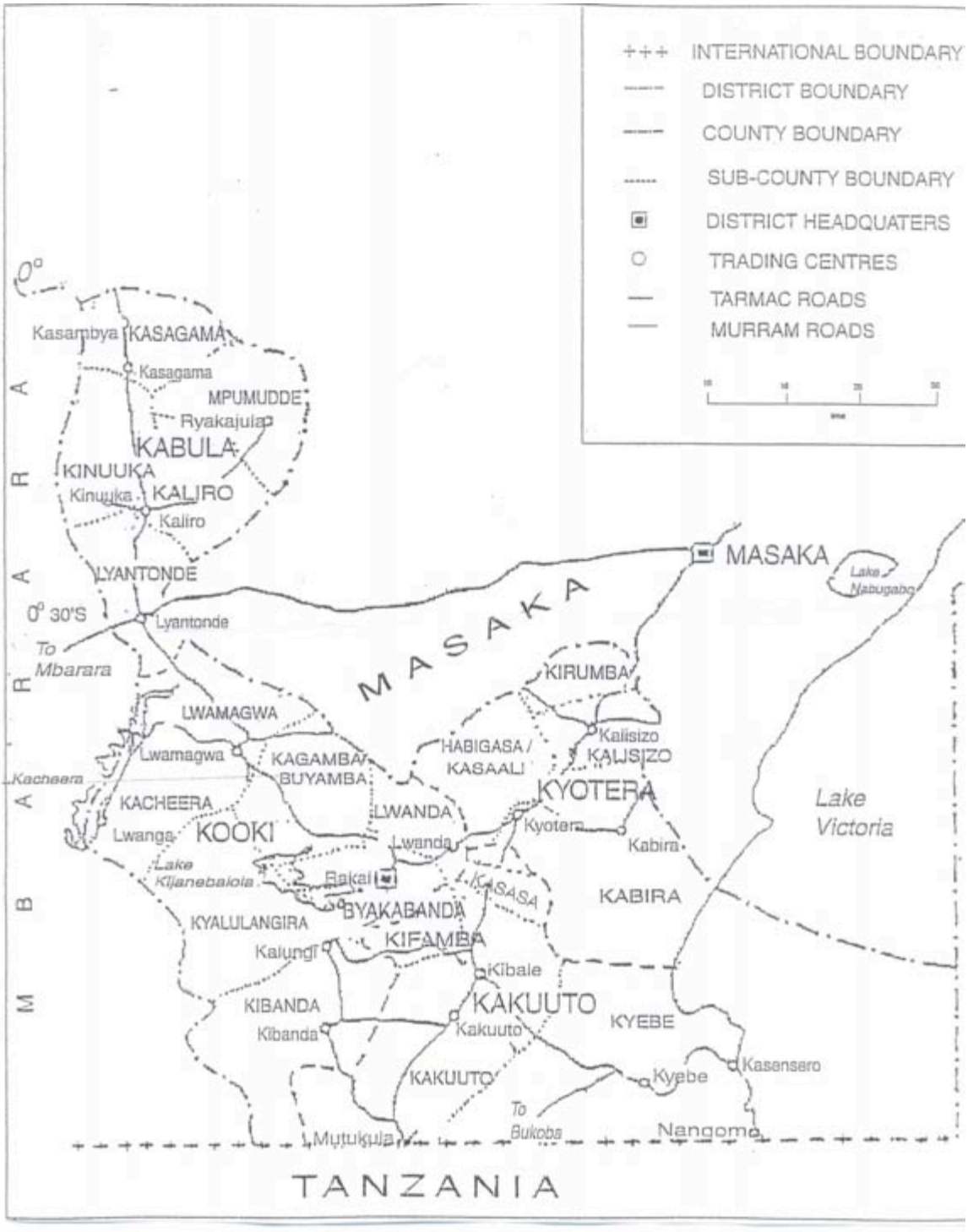
_____
Paz G. Buttedahl, PhD
Academic Supervisor and Academic Lead, MAHSP Program
Or

_____
Gregory Cran, PhD
Director, School of Peace and Conflict Management

ROYAL ROADS UNIVERSITY
March 2006

© Alanna Kathleen Jorde, 2006

MAP OF RAKAI



Front cover: Orphaned baby in Kooki county of Rakai district
Photo credit: Unless otherwise indicated, all photos by Alanna Jorde

ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBO	Community-based Organization
CHH	Child-headed Household
HIV	Human Immunodeficiency Virus
MHSP	Master of Arts in Human Security and Peacebuilding
NGO	Non-governmental Organization
OVC	Orphans and other Vulnerable Children
PARDI	Participatory Action for Rural Development Initiative
PWA	Persons living with AIDS
RRU	Royal Roads University
UNAIDS	Joint United Nations Program on HIV/AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations Children's Fund
USh	Ugandan Shillings

TABLE OF CONTENTS

FOREWORD 1

INTRODUCTION: An Overview of the AIDS epidemic in Rakai district 3

PARDI: A participatory, people-centred response to HIV/AIDS 10

IN THEIR WORDS, BY THEIR HANDS: The most pressing human security challenges of children affected by HIV/AIDS as revealed through their drawings, letters, skits and songs . .22

CHILDREN IN JEOPARDY: The impact of HIV/AIDS on children 39

CONCLUSION: Lessons learned and the recommended way forward 52

APPENDICES 74

APPENDIX A: Facts & Figures Uganda and Rakai 74

APPENDIX B: PARDI 79

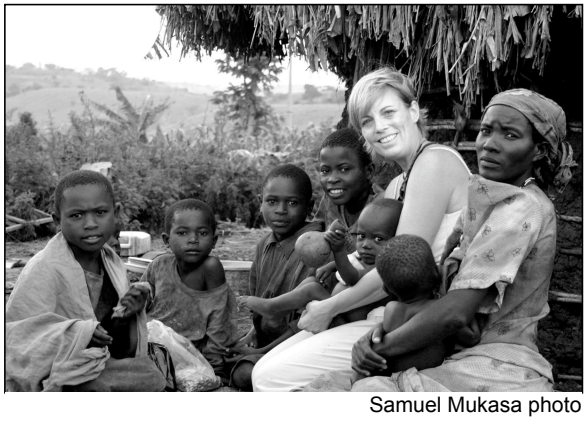
APPENDIX C: Field Activities 86

APPENDIX D: Field Experience Assessment Form 105

REFERENCES 108

FOREWORD

In the spring of 2004, I suffered one of the worst anxiety attacks of my life. My heart raced, I was sweating profusely, my breathing was laboured, my chest felt as if it was about to implode and I seriously wondered whether the walls of the lecture hall where I was sitting were defying the laws of physics and closing in on me. As I listened to my Royal Roads University classmates explain the catastrophic effect AIDS has had on Africa, I had an overwhelming urge to flee.



Samuel Mukasa photo
The author with AIDS orphans in Kooki county, Rakai district.

The statistics are chilling. One in seven of the world's people live in Africa yet they account for two thirds of all people living with HIV and AIDS and analysts say the pandemic has yet to peak. The death toll in sub-Saharan Africa is staggering, roughly equal to the fatalities of eight South Asian tsunamis combined, over 2.3 million people in 2004. The number of children who died of AIDS in Africa that same year exceeded half a million and the number of AIDS orphans is growing; projections for 2010 suggest the numbers will more than double from 2000 levels to nearly 19 million. In the hardest hit countries in Africa, a 15-year-old boy has a 50 per cent chance of dying of AIDS. A 15-year-old girl has a one-in-three chance of surviving to her mid-30s. The pandemic poses a greater human security threat to most Africans than war. In 1998, 200,000 people in Africa died in armed conflict while more than two million died of AIDS. While HIV-positive people in Canada and other rich nations have easy access to state-of-the-art health care treatment and life prolonging anti-AIDS drugs, most in sub-Saharan Africa are lucky to receive aspirin as they die agonizing deaths at home or two or three to bed in over burdened medical wards. Average life expectancy in sub-Saharan Africa would now be an estimated 62 years if AIDS did not exist; instead, it is estimated at 47 years. In a few of the hardest hit nations, average life expectancy has declined by over half.

During a break in the presentation, I made my escape, seeking comfort under the protective canopy of a nearby old growth rainforest to contemplate the enormity of the problem. A cool ocean breeze tussled the leaves as I paced, wondering, as the sun cast a warm glow over my idyllic surroundings: How is it possible for the suffering of millions to be so callously disregarded? Faced with the worst scourge ever to strike earth, at a time when dialogue and action are urgently needed, how can humanity choose to react with only silence and apathy? In the history of humankind has the magnitude of a tragedy so dwarfed the scale of the response?

Perhaps it was providence, most definitely an ironic twist of fate, but a little over a year after experiencing debilitating angst over these very questions, I found myself staring the AIDS pandemic in Africa directly in the face, literally and metaphorically. By design or by accident, on June 5, 2005, I became the volunteer media relations officer/resource mobiliser for Participatory Action for Rural Development Initiative (PARDI)[1]. I accepted this position with all of the hubris, naiveté, idealism and sense of entitlement you'd expect from one who won the lottery of longitude and latitude by being born and raised in an affluent, privileged, predominantly white nation. I fully intended to make my mark on the organization and the people PARDI assists. Instead, it is they who have left an indelible mark on my consciousness and conscience.

In response to the desperate needs of those affected by HIV/AIDS in Rakai district, PARDI emerged out of necessity, dedication and compassion to fill gaps in prevention, care and support, which in richer countries would be the responsibility of public health and social services. The community-based organization has shown incredible steadfastness and creativity in providing a variety of essential services to the most vulnerable members of their community — people living with HIV/AIDS, widows, the elderly and children. In its own modest way, my hope is this report will highlight the valuable contributions civil society can make as active partners in the response to the pandemic so that a case can be made for the critical work of community-based organizations like PARDI to be not only supported but also strengthened.

Although PARDI's aim isn't strictly to improve the lives of children affected and infected by AIDS, I felt compelled to focus, in particular, on the courageous struggle of children. The impact of AIDS on children has been overlooked so much so that last fall UNICEF declared children to be the "missing face" of AIDS. I've included as many photographs of these "faces" as space would allow in an effort to begin addressing this injustice. As much as I could, I've also tried to allow these children and others who are the focus of this report to speak in their own voices about their lives, experiences and circumstances. Their stories are presented in narrative case studies and expressed more creatively in the lyrics of their music, the scripts of their drama skits and their drawings and letters. Finally, as impossible as it would be, many of these "missing faces" have urged me not to forget them when I leave Uganda. I hope this report inspires others not to forget these innocent victims of one of humanity's worst tragedies as well.

[1]In addition to my field placement with PARDI, I wrote a regular column for CBC.ca and participated on a research project funded by the Canadian International Development Agency during my stay in Uganda. The columns are included in Appendix C: Field Activities, pages 97-104.

INTRODUCTION:
An overview of the AIDS epidemic in Rakai district

> *"AIDS is both a direct threat to the physical and mental health of many Africans and an overwhelming challenge to the economic development of African families, communities and nations. Although manifested in the individual, HIV/AIDS affects health systems, family and community structures, education, agricultural production, national budgets, business development, national security, and global trade."*
>
> HIV/AIDS in Africa: What Works Conference Report
> (Center for Global Development and John Snow, Inc. 2003: 1)

> *"Extensive AIDS epidemics are both a consequence of uneven development and serve to undermine progress, exacerbating existing inequalities and generating untold misery. AIDS sets the development clock back by decades in hard-hit countries."*
>
> *Jackson (2002: 36)*

> *"AIDS … spawns impacts now and in the future that are hard to predict or quantify today."*
>
> Commission for Africa (2005: 202)

Uganda is often cited as *the* success story in sub-Saharan Africa in its efforts to curb the spread of HIV/AIDS. One of the first countries in Africa to be hit by the pandemic, Uganda was also the first nation on the continent to reverse prevalence trends. The country was taking bold and decisive action at a time when the disease was still poorly understood and other nations were denying the very existence of AIDS. In 1986, Uganda not only spoke publicly about the nature and extent of the disease in the country at the World Health Assembly, the national government launched a National AIDS Control Program. The aggressive national anti-AIDS strategy is credited with bringing a "spreading and generalized epidemic under control with strong leadership, comprehensive education with a clear message (ABC — Abstain or delay sex, Be faithful, use a Condom) and making the response part of everyone's day to day life" (Commission for Africa, 2005: 201). It is widely believed that prevalence levels have dropped from a high of 30 per cent in the early 1990s to its current level of around five per cent as a result of profound and rapid changes in attitudes.

Still, despite quantifiable progress in fighting the disease, this success story cannot negate the suffering generated by HIV infections and their destructive effects on the economic and social fabrics of society. Nowhere in the world has the disease been more ravaging and disastrous than Uganda's Rakai district. Located in southwestern Uganda, Rakai is widely regarded to be the epicenter of AIDS in the country. The first AIDS cases in Uganda were identified in Rakai district in 1982. By the late 1980s the district had one of the highest HIV

infection rates in the world. Generally, prevalence levels continue to be consistently higher in Rakai district than the national average and, even more disturbing, most recent data suggest prevalence levels are actually increasing in the district. According to the Rakai Community-Based HIV/AIDS Project, prevalence levels increased from 12 to 15 per cent in 2005 (personal telephone text message, Dec. 1, 2005).

Africa's high AIDS prevalence defies explanation

It is worth nothing that although it is an irrefutable fact that the HIV/AIDS pandemic is an unmitigated tragedy and development disaster in Africa, a solid explanation for Africa's extraordinarily high prevalence rates still confounds analysts. Unlike North America, where AIDS is deemed to be a disease that predominantly afflicts homosexuals and intravenous drug users, the principal means of HIV transmission in Africa is heterosexual intercourse. But empirical evidence does not support the widely held hypothesis that there is more sexual activity outside of long-term stable relationships in Africa, and currently there is a great deal of speculation about other possible explanations. "Perhaps the sexual networking is different in Africa (for example, there are more relationships between older men and younger women and more concurrent relationships, although not more lifetime partners). Perhaps HIV/AIDS is transmitted more easily in Africa because the population has other untreated ailments (malaria, other sexually transmitted diseases), or because men are much less frequently to be circumcised [since circumcision seems to protect against transmission of the disease], or because condoms are less frequently used in casual sexual relations. Perhaps the viral subtypes (known as clades) are different in Africa. (Sachs 2005: 2005)"

What is certain is, thus far, two main types of HIV have been discovered — HIV-1 and HIV-2 as well as 11 distinct subtypes of HIV-1 — and the patterns of geographical distribution of these subtypes varies significantly (Jackson 2002: 41-42). Subtype B is the most common subtype found in the Americas, Europe, Japan and Thailand (and perhaps not surprisingly it tends to be the primary focus of research into the development of an AIDS vaccine). It's possible that subtype B is transmitted readily through intravenous drug injecting and anal intercourse, but less efficiently through vaginal intercourse, which could explain its relatively low prevalence in sub-Saharan Africa. HIV-2 — which has been identified in much of West Africa and in low levels in the rest of Africa and elsewhere — causes AIDS, but it appears to take much longer to lead to disease and to be less easily transmitted sexually and from mother to baby than HIV-1.

AIDS and Poverty: Causation runs in both directions

Historically, Rakai has been one of Uganda's most impoverished districts (Rakai Community-based AIDS Project 2004: 7-9). The communication network, district infrastructure and basic services such as health, water and education have only just begun to improve in the district and it is estimated that less than five per cent of the population have access to electricity. Subsistence cultivation of bananas, sweet potatoes, cassava, maize and beans is the principal means of livelihood for 70 per cent of Rakai's 471,806 inhabitants. Poverty is endemic in the district. Over 70 per cent of the households are estimated to survive below Uganda's subsistence level of 5,000 Ugandan Shillings (USh) or $3 US per week. Many of the problems associated with HIV/AIDS have been exacerbated by poverty; at the same time, AIDS is a significant cause of poverty in the district. Put another way, causation runs strongly in both directions.

A young AIDS orphan (right of grave) mourns the death of her father with community members in Kooki county.

Analysts (Jackson 2002; Sachs 2005; Commission for Africa 2005) agree that the reason the pandemic has had such a devastating effect on Africa is because the disease primarily affects the most productive age range in the population. Like other areas of the continent where the pandemic is the most serious, high HIV infection rates among people in the productive age group have seriously weakened the labour force in Rakai. Prolonged sickness and gradual failing health due to the disease has resulted in absenteeism and high labour turnover as people living with AIDS (PWA) become too ill to work and become increasingly dependent on others to take care of them. This negatively affects production and productivity in agriculture, industry, service and informal sectors, which has a cataclysmic impact on family revenue and food security at the household level to say nothing of the emotional and psychological trauma the disease inflicts.

For many in Rakai, the crisis of being sick with AIDS or having to care for a family member who is infected with the disease is enough to tip them over the edge of bare survival into starvation and destitution. This is especially true in rural households, which are forced to cope by sacrificing their long-term security — pulling children out of school, selling off land and other assets and exhausting their savings. The decreasing ratio of productive adults to dependent children deepens poverty even more

because having too many dependent children in relation to productive adults makes it difficult for people to secure sustainable livelihoods and move out of poverty. This puts increased pressure on the land and other resources.

The effects of HIV/AIDS are worsened by poor access to health care. About 40 per cent of people in Rakai district do not have access to health care facilities either because they cannot afford to pay transportation costs to get to and from facilities, they cannot afford the fees associated with treatment, or both. The cost of treating one HIV/AIDS patient currently ranges from 370,00 to 1.28 million USh ($214-$740 US) per month, which greatly exceeds what the majority of those infected by the virus can afford. Moreover, the large volume of patients seeking services from an already overstretched health care sector is overwhelming personnel in the health care sector. The stigma attached to HIV/AIDS worsens an already difficult situation and results in the neglect of some people who show clinical signs of AIDS.

Furthermore, just as AIDS has a negative impact on development, so can development processes sometimes increase the risk of becoming infected. For instance, in countries like Uganda, the spread of HIV/AIDS can be traced along major trade routes. HIV infection rates are higher along main roads and especially popular transport routes. In Rakai district, infection rates are higher in trading centres, particularly those that are common stops for truckers headed to or from southwestern Uganda, Tanzania, Rwanda and Congo. In additional to good transport and trade routes that facilitate considerable population movement, several other factors make Rakai district a high-risk environment for HIV transmission; namely, it is an area characterized by poverty and inequalities of wealth, poor health services, unequal gender relations, and weakening family structures.

Households, CBOs bear the burden of care

For a variety of reasons — human or resource constraints, the terms under which donors operate, etc. — external support to those most adversely affected by HIV/AIDS remains unfocused, fragmented and sporadic rather than coherent, coordinated and comprehensive. Projects that currently exist in Rakai are insufficient to meet the need and may provide services to some, while others are completely neglected. Consequently, households, the traditional extended families, and local communities — especially community-based organizations (CBOs) and self help groups — bear much of the increased burden of addressing the complex range of problems associated with HIV/AIDS. The principle manifestation in Rakai is the growing number of orphans[2] and elderly people caring for orphans. It is estimated that 25 per cent or over 40,000 of the children in Rakai district are orphans due to AIDS. The well-being

[2] The Ugandan government defines an orphan as a person under the age of 18 who has lost one parent (single orphan) or both parents (double orphan).

of these children depends significantly on the capacity of the community to support and raise them. Hagaba Richard, PARDI field program officer, explains the crisis this way. It's as if the famous African proverb, "An elephant can never fail to carry its tusks", has been turned upside down. The tusks have become too heavy for the elephant and the role of parenting is shifting to community-based non-governmental organizations and children. For the unfortunate children who lose their parents to AIDS, the mantle of parenting is automatically passed on to them.

Before AIDS, the term "orphan" had little resonance in most African cultures because a parents' sisters and brothers, who are referred to as aunts and uncles in the West, are also deemed to be mothers and fathers of children. Thus, provided an aunt or uncle can care for a child, the child is not an orphan. According to *Baganda* tradition, which is the majority tribe in Rakai district, the clan either appointed a surrogate parent locally referred to as "omukuza", the orphans were divided among siblings of the deceased, or the orphans became the responsibility of grandparents, especially on the paternal side. But the rapid depletion of the adult population in the district due to AIDS coupled with an unprecedented increase in orphans is overwhelming traditional cultural support mechanisms to the point of almost complete exhaustion. Today, many would-be surrogates have died, are ill or are already so overburdened with their own family members dying of AIDS they simply do not have the capacity or resources to take care of more children. This had led to a new social order, whereby children — once protected because they were perceived to be the most vulnerable members of society — are left to fend for themselves. Increasingly, children find themselves heading a child-headed household[3] (CHH) or belonging to a household headed by a sibling under the age of 18 or an elderly grandparent whose own poverty, advanced age and/or ill health makes them ill equipped to care for them. The needs of children affected by AIDS, particularly the so-called "orphan generation", remain largely hidden and go largely unmet.

Yet, if the needs of these children continue to go unmet, the consequences will be dire not only for themselves but also for the society in which they live. These children are growing up with little sense of basic human security. They are usually poorly educated, have low self-esteem, and possess limited social and life skills. They have minimal opportunities to pull themselves out of poverty, and little chance to become productive, self-sufficient citizens and parents. Instead, they are likely to increase instability since research suggests these children are more likely to turn to crime and create other social problems in society at large, perpetuating the human rights abuses they have suffered. It is likely there will be a corresponding increase in the number of

[3] A child-headed household is defined as a household, headed by a child under the age of 18, which is recognized by the local community as being independent. Even if an adult lives in the house, it is the child who takes full responsibility for all duties normally performed by an adult in conventional households.

street children and child sex workers, exploitation of girls and women, early marriages, and unwanted pregnancies, thus creating a further generation of ill cared for children born to these impoverished parents. The vicious cycle of deprivation and high HIV infection rate will repeat itself, but at greater intensity because the cushion of a relatively uninfected elderly generation will no longer be around. In other words, lack of sufficient care now is a recipe for increased spread of HIV infection in the future, and for increased social instability. (Jackson 2002: 257-258)

AIDS: A significant threat to human security in Rakai district

In summary, as Nef's human security/insecurity analytical matrix predicts, the impact of HIV/AIDS on Rakai district has been profound and complex and can only be adequately comprehended as a complex interplay of dynamic and interconnected multurally-reinforcing dysfunctions (Nef 1999). UNAIDS (2001) has reported that HIV infection levels are generally highest where access to care is lowest, and social and economic safety nets that might help families cope with the impact of the epidemic are badly frayed. Tragically, Rakai is a textbook example of this. HIV/AIDS is destroying traditional cultural coping mechanisms, increasing poverty, reducing family income and productivity, which has not only led to a further shrinking of the adult population, but also widened and increased dependency on scarce resources and vulnerability among the elderly and children. This not only worsens the plight of the orphans and other vulnerable children (OVC) but also undermines the observance of children rights. It is within this context that Participatory Action for Rural Development Initiative (PARDI) is working tirelessly, resolutely to address one of the most significant threats to human security and community development in Rakai district.

How this report is organized

This report aims to provide up-to-date information on the effect of the HIV/AIDS epidemic in Rakai district and particularly the counties where PARDI is working, on responses and gaps and on the opportunities and challenges PARDI is encountering. The report aims to examine this urgent humanitarian crisis from an often overlooked and ignored perspective — the marginalized, vulnerable individuals who courageously struggle to survive in the face of unimaginable adversity. Moreover, this report presupposes that these people *can be* and *ought to be* agents of social change and economic progress rather than passive recipients of aid or, in other words, given the chance they can effectively shape their own destiny and help each other.

It should be noted that PARDI played a significant role in planning and carrying out field research and assisting with the data analysis upon which much of this report is based. In that way, the report rejects the positivist model of the

objective researcher and passive research subjects and embraces instead the notion that research can only be strengthened when the perspectives of those being studied have input into the design and conduct of research. Since most of the people PARDI supports do not speak English, PARDI staff also played a critical role as translators in the field. A variety of research techniques were used in the development of this report, including: an analysis of current, relevant studies, reports and books about vulnerable people infected with and affected by HIV/AIDS in Africa; an examination of the lyrics of songs and scripts of skits performed by drama and choir groups made up of OVC; an assessment of the human security issues facing OVC as revealed through their personal drawings and letters; observing those who are the focus of this report in their natural environment and participating in activities in the field from June 2005 to March 2006 as PARDI's media relations officer/resource mobiliser.

The report begins by outlining the nature and extent of PARDI's efforts to assist those infected with and affected by HIV/AIDS in Rakai district. The next section focuses on the most pressing human security challenges of OVC and CHHs as revealed in their drawings, letters, songs and skits. The report goes on to describe, more generally, the impact of HIV/AIDS on children. The concluding section builds a case for a made-in-Africa response to the epidemic, outlines key lessons learned and suggests recommendations for the way forward. The report wraps up with some final remarks about my field practice. An ancillary package that accompanies this report includes a CD with a PowerPoint presentation detailing PARDI's work as well as short movies of a choir and drama group, made up of OVC that PARDI assists, performing songs and skits.

PARDI:
A participatory, people-centred response to HIV/AIDS

> *The first response to the problems caused by HIV/AIDS comes from the affected children, families, and communities themselves, not from government agencies, NGOs or donors.*
>
> Hunter and Williamson (1998: 4)

> *When it comes to caring for people with HIV and AIDS, the richest resource a country has is, without question, the compassion of its people.*
>
> UNAIDS (2000a: 60)

PARDI emerged out of necessity, dedication and compassion in 2001 in direct response to the desperate needs of those infected with and affected by HIV/AIDS, and particularly the most vulnerable and underserved people in the community. A non-governmental community-based organization (CBO) that is registered with Rakai district government authorities, PARDI currently operates in Kooki and Kabula counties in Rakai district and Mawogola county in Sembabule district. PARDI is endeavouring to fill gaps in essential services since most of the organization's target beneficiaries do not receive assistance from government agencies or other non-governmental organizations (NGOs).

A PARDI volunteer takes note of the needs of an elderly widow.

PARDI's objective is to engender meaningful, fundamental and sustainable change particularly at the community and household level using a strategy of "bottom up", "people-centred" development. This strategy assumes development is a process of progressive and human-centred quantitative and qualitative transformation of society and therefore communities ought to be regarded as active rather than passive participants in the development process. In this way, PARDI's "bottom up", "people-centred" strategy rejects, implicitly at least, generalized and deterministic modernization and dependency models of development, which presuppose that economic growth propels development in a linear fashion and change comes from the top down.

Currently, approximately 21 full-time and 51 part-time volunteers carry out PARDI's activities. A board of trustees, in collaboration with a program officer, makes PARDI's key management decisions. The program officer also supervises three project officers who are responsible for activities related to community development, OVC and AIDS support and education. The CBO relies primarily on financial donations and material support from volunteers and well-wishers from Uganda and abroad to operate. A network of volunteer counsellors and members of the local council I (LCI), who are representatives of the local government system, link PARDI to the grassroots community. In stressing the importance of "bottom up" planning in response to the most pressing issues that affect the community, PARDI meets regularly with beneficiaries, guardians and other partners to exchange ideas, opinions and information. Community members who are targeted for support are involved in the process of identifying key problems, assessing and prioritizing needs, and brainstorming possible solutions to the problems identified.

Table 1: The impact of AIDS on vulnerable people in Rakai District

AIDS increases poverty and long-term insecurity at the household level in terms of physical, emotional and psycho-social suffering and distress. AIDS also leads to domestic conflicts and family breakdowns. The human security impacts of AIDS on the vulnerable people PARDI seeks to support in Rakai district vary but commonly involve:

- **Loss of income, remittances and productive labour leading to increased poverty and poorer nutrition**
- **Increased expenditure on health care, transport and funerals**
- **Reduced expenditure on food, clothing, school, shelter and other basic necessities**
- **Drawing down of savings and sale of assets**
- **Emotional and mental stress**
- **Increased workload on women and children**
- **Increasing number of elderly caring for orphans and children caring for themselves in child-headed households**
- **Children drawn out of school**
- **Children selling their labour in exchange for money and/or food to support their families**
- **Social inequalities between children**
- **Flight of orphans to urban centres in search of work**
- **Early marriages, especially for girls**
- **Risks of sexual and economic exploitation as well as physical, psychological, sexual and other human rights abuses of children**
- **Risks of stigma, isolation and rejection**

Uplifting standards of living

Since its inception, PARDI has grown both in size and scope of its activities according to community needs, scaling up support to vulnerable community members, especially children living alone in CHHs and other children affected and infected by AIDS. Today, PARDI aims to improve the lives of approximately CHHs and over 2,000 orphans, 150 people living with HIV/AIDS (PWA) and 132 widows and elderly people who courageously struggle to survive chronic hunger and malnutrition, disease, poor access to safe drinking water, inadequate shelter and other life threatening challenges. The organization employs a multi-sectoral, integrated and holistic approach in an effort to uplift the standards of living of those most devastated by HIV/AIDS through self-help strategies and community-based initiatives that involve: community mobilization; psycho-social counselling; financial and material support as well as income generation; skills and vocational training; counselling in HIV/AIDS prevention and care; treating opportunistic infections (OI) and providing palliative care; referrals to voluntary HIV counselling and

testing services and pre and post-test counselling; home-based care.

In a practical "on-the-ground" sense PARDI's activities include:

•Provision of critical basic needs such as food, clothing, bedding and medication.
•Training community members in improved agricultural methods and distribution of high yield seeds, anti mosaic cassava cuttings, goats, and chickens to improve food security.
•Health outreach, including psycho-social counselling, education about antiretroviral therapy (ART), AIDS management, vocational therapy and nutrition.
•HIV/AIDS awareness and sensitization programs, including children's performance art groups made up of orphans and vulnerable children (OVCs) that educate through song, dance and dramatic skits.

PARDI convinced a community benefactor to donate land and facilities that were converted into Valley Primary School, which opened in the fall of 2004, in Lyantonde town.

•Establishment of a community network and field outreach program to identify OVCs and other vulnerable people who are in critical need of support.
•Recruiting and training volunteer counsellors.
•Mobilizing support from key community stakeholders to assist vulnerable people through the provision of land for orphanage centres, food production, and a school; donations of money, livestock, food, clothing, scholastic materials, etc.; and, the construction of homes and water tanks.

One of PARDI's most important functions is delivering HIV/AIDS prevention, care and support services as well as psycho-social, emotional and material support directly to those in need in their homes and community. The vast majority of the people PARDI assists are too poor to obtain care and treatment from health care professionals and they lack access to even the most basic medication, nursing care, and relief of symptoms. By reaching out to vulnerable people and treating AIDS like any other social, health and welfare issue in the community, PARDI also helps reduce the stigma, isolation and discrimination attached to the disease, so that those affected and infected are encouraged to openly seek the help they need. This, in turn, reinforces community awareness of AIDS, which contributes to HIV prevention efforts. That said, the critical problem is usually not so much the disease itself as poverty. Thus, PARDI's outreach services also provide an entry point into the community to tackle the most pressing human security issues through meaningful and sustainable development, which is crucial to prolonging survival with HIV infection, helping people cope with AIDS and, for a myriad of complex reasons, helping prevent HIV transmission in the first place. PARDI also nurtures self-reliance among vulnerable people affected and infected with AIDS by building their capacity to support themselves. This is achieved through the creation of income-generating activities, education and vocational skills

training, training community members in improved agricultural methods, and the distribution of high yield seeds, anti-mosaic cassava cuttings, goats and chickens. These activities are especially important for OVC because they discourage children affected by AIDS from fleeing to urban centres in search of work. Research (Rakai Community-based AIDS project 2004) suggests OVC survive better in rural areas than urban centres.

PORTRAIT OF A VOLUNTEER

Yusuf Matovu has a profound empathic understanding of the desperate struggle of children who have lost their parents to AIDS. He has personally experienced their hopes and fears. Yusuf, 27, has no recollection of his own parents because they died of AIDS when he was so young. He grew up on the streets of Mbarara in southwest Uganda until the authorities caught up with him and he was imprisoned.

Since he was extremely impoverished and didn't have money to pay for an education, he was made a dependant of a school in Mbarara. He managed to complete S4 when his school sponsorship stopped. He tried growing food to pay for his school fees but cultivating the land consumed so much of his time he eventually had to drop out.

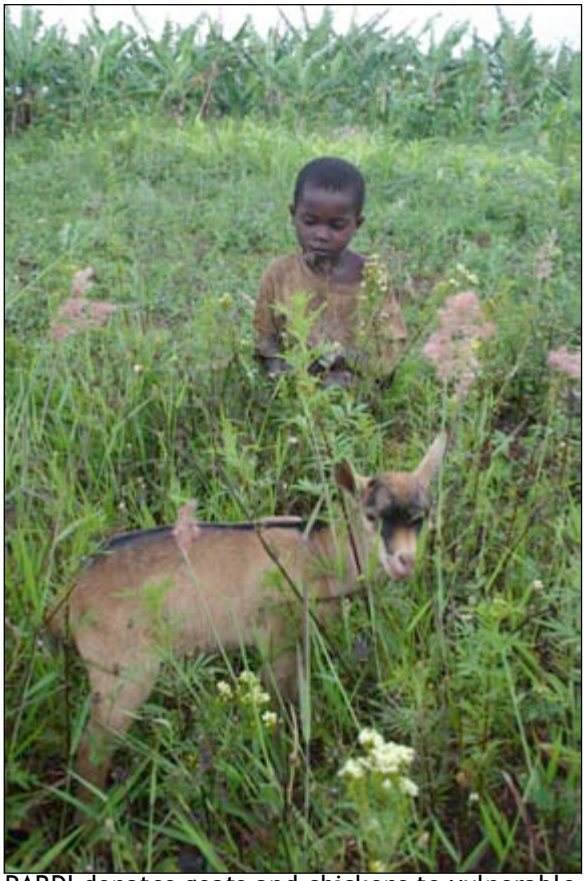
For the past five years Yusuf has devoted his life to improving the lives of vulnerable people infected and affected by HIV/AIDS in Rakai district's Kabula county. From cultivating food for orphans, to counselling PWAs in their home, to carrying the coffins of a deceased community members several kilometres for their burial, Yusuf is eager to carry out any task required of him. "My family is everyone; everyone is my family. I realized I was born to serve," he says.

Volunteer counsellors: the backbone of the organization

PARDI actively recruits volunteer counsellors from the communities in which the people in need reside to provide these services and they are the backbone of the organization. Their most critical tasks are identifying vulnerable people; mobilizing the community; disseminating information and support; acting as foster parents to orphans and checking in on them regularly, which enhances the coping mechanisms of CHHs; and, being available when crises occur. There are several significant benefits to using community volunteers in the provision of services. In addition to maximizing community involvement and ownership in PARDI's programs and making the most of existing resources, involving volunteers promotes a sense of shared responsibility in addressing the problems associated with the epidemic. The recruitment of volunteers encourages sustainability over time because community members are poised to take over in the event CBO phases out its operations. Volunteers also have the opportunity to raise their profile in the community as well as acquire valuable skills applicable to other areas of their lives and experiences that potentially can help them secure paid work. Moreover, they are in a better position to help their own families and themselves if they become affected by AIDS.

All counsellors must be over 18 years of age and they must have obtained at least an 'O' level education. PARDI also selects volunteers who are known to be very responsible people,

who have demonstrated they can support themselves and who, preferably, own land that can be used to grow food for distribution to beneficiaries. Prior to becoming a PARDI counsellor, volunteers undergo extensive training that takes anywhere from one to three months depending on resources available. They are also required to complete refresher sessions every six months to help them keep abreast of the latest developments in HIV/AIDS treatment and care. Each counsellor keeps records of the location and names of clients in each household they visit and their number of visits to the home. The number and frequency of their visits varies depending on the severity of the challenges each family faces and the number of clients the counsellors support.


PARDI donates goats and chickens to vulnerable people for income generation and to improve food security.

In assisting vulnerable people infected with and affected by the epidemic, PARDI's endeavours to consider the whole person — the mind, body, spirit — and to address his or her needs using an integrated, multi-sectoral and holistic approach. Therefore, in addition to up-to-date information on care, treatment and prevention of HIV/AIDS, counsellors learn a variety of skills to address the needs of their clients, including:

•Strategies to help people infected with and affected by HIV/AIDS help themselves.
•Techniques to help clients cope with problems of stigma and discrimination, guilt, anger, blame, rejection and isolation as well as multiple deaths in one family, and the enormous strain of repeated ill health, death and bereavement.
•Tools to assess the critical needs of clients and to provide for their material, emotional, psycho-social, practical, nutritional, spiritual and financial needs.
•Nursing care methods and advice on accessing medical services and supplies.
•Techniques to help clients prepare for the future, regarding inheritance, child care, economic survival and other long-term concerns.
•Mobilization and leadership skills.

HIV/AIDS sensitization and awareness

Although beliefs and attitudes about HIV/AIDS are changing in Uganda, some of PARDI's clients still do not know much about the disease. Fear and confusion over the devastating epidemic still exist, fuelling prejudice, discrimination and rejection. Those who have HIV or care for a family member who has AIDS are still perceived by some to be threat to themselves, their families and the wider

community. Others are convinced HIV/AIDS is the result of witchcraft or angry spirits. Sensitizing communities, families and individuals about the disease is therefore a critical component of the work of volunteer counsellors not only because awareness significantly reduces the stigma attached to AIDS, it is also crucial to prevention because it helps people understand what they need to do to safeguard themselves and others against the virus.

Volunteer counsellors help dispel myths and misperceptions as well as correct wrong information about HIV/AIDS to ensure clients have an accurate understanding of the virus, disease and its transmission. They also identify the risk factors for HIV and help clients understand those aspects of their behaviour needing change to protect themselves and others and try to motivate them to achieve these changes. They refer clients to voluntary counselling and testing services at nearby health centres and provide pre and post-test counselling. They assist those living with the virus and their family members adjust emotionally to HIV/AIDS, help out in a variety of ways with practical and material problems that arise, refer clients to other potential sources of help, and mobilize resources when possible. Volunteer counsellors also encourage people to think about the future and to make appropriate plans for themselves and their dependents.

Prior research in two other districts of Uganda (Gilborn, Nyonyintono, Kambumbuli and Jagwe-Wadda 2001) found that most older children want parents to reveal they are HIV positive and parents are also predominantly in favour of disclosing their HIV status to their children because they value honesty, talking about prevention and being able to prepare for the future. PARDI staff report that parents are reluctant to disclose their HIV status to their children unless a counsellor intervenes early and provides support with and advice about discussing this difficult issue with their children.

Volunteer counsellors assist an orphan who is sick with malaria.

Self-help

Since PARDI's resources are limited and often in short supply, the organization isn't always in a position to provide material or financial support. But volunteer counsellors can help PLA live positively with HIV/AIDS by encouraging them not to give up hope, to take care of their physical health and well-being, and to seek support from others. Volunteers often provide advice to PWA on how they can safeguard their health through healthy lifestyle choices such as staying active and busy; eating a well-balanced diet; reducing anxiety and coping with stress; maintaining good hygiene; and, avoiding unprotected sex, smoking, heavy drinking and recreational drugs. A growing

body of scientific evidence suggests these self-help strategies yield direct health benefits as well as psychological benefits. All activities that prolong the life of PWA and their ability to care for themselves and their families obviously also benefit their children.

Orphanage centres

PARDI works with 13 orphanage centres, which also play a vital role in the provision and delivery of outreach services to vulnerable people infected with and affected by HIV/AIDS and the communities in which they live. In most cases, community members have donated the land and facilities for the centres. These centres are easily accessible community gathering and meeting places for OVC, PWA and the neighbourhood. They tend to become a refuge especially for OVC because volunteers who operate the centres make a point of creating an environment in which children and others infected with and affected by HIV/AIDS feel safe, secure, and free from humiliation and stigmatization as well as active citizens of the community. The children develop close relationships with other OVCs and regard them as brothers and sisters. An important activity of the centres is the facilitation of children's performance art groups, which educate through song, dance and dramatic skits. Some of the centres are equipped with rudimentary facilities to house orphanage centre volunteers and a limited number of OVC who may need emergency shelter. Most of the centres also have gardens that produce food for distribution to vulnerable people and which are also used to teach improved agricultural practices to OVC and others. Some of the centres also provide primary education and vocational training to OVCs and are equipped with water tanks where the nearby community can access safe drinking water. Since the vulnerable people PARDI are too poor to have telephones, the centres are also important communication centres, where vulnerable people can express their needs and learn about social services and other resources they might need to access.

Table 2: PARDI Orphanage Centres

CENTRE NAME	NUMBER OF ORPHANS
Mukisimba	98
Lusaso	103
Kijako	216
Ntalama	82
Kibuka and Kyanika	227
Bugona	104
Kilaangira	107
Kakundi	201
Ssamanya	377
Valley	59
Kalagala	93
Matette	356
TOTAL	2023

Source: PARDI, personal communication, Hagaba Richard, January, 2006

Home-based care

A new holistic and integrated approach to home-based care (HBC), introduced a year ago by some of PARDI's volunteer counsellors includes: nursing care; nutrition; promotion of the living; counseling; ART, when available; physical

therapy; AIDS management; memory book; will making; prayers; and, management of income generating activities.

Memory books — put together by parents, their children and others — contain photographs, documents, anecdotes, sketches, mementos and other family information and messages that the parent thinks is important to include. Memory books are designed to help PWA help their children cope with bereavement. Memory books also provide children with a permanent link to their parents and the extended family when they are orphaned, thus addressing an important psycho-social need for both PWA and the orphans they leave behind after their death.

Currently, very few people in Uganda have prepared wills prior to their death. Although writing wills is not a traditional cultural practice in Uganda, it is believed that doing so may reduce community conflicts that arise after the death of a PWA, such as property grabbing, which is explored more on page 43 in the section "Children in Jeopardy: The impact of HIV/AIDS on children".

The Ugandan government distributes a limited supply of free antiretroviral drugs (ARVs) to some of the PLAs PARDI assists. Generally those who are receiving ART respond very well to the treatment, especially with encouragement from volunteer counsellors. PARDI volunteers report that sometimes patients consider quitting the treatment due to unpleasant side effects, but counsellors persuade them to continue taking the medication and eventually their health improves significantly. It's difficult to accurately establish the number of people who are receiving ART in the counties PARDI operates since reliable statistical information is not available. PARDI estimates only about four per cent of those who need the life prolonging drug treatment are currently receiving it. The CBO confirms what analysts have suggested that in Uganda, like other nations in sub-Saharan Africa, "the demand for treatment access from the wealthy ensures that [ARVs] are available — often in an ad hoc, unregulated fashion" (Jackson 2002: 75). PLAs who have to pay for the medication often are forced to exhaust their savings and sell off all of their assets to purchase ARVs. But once their funds disappear, so do the drugs. If the medication was available for free to all those who need them, "the disease would be more manageable, they would live longer and their children would have a brighter future," says volunteer Yusuf Matovu (personal communication, Jan. 22, 2006).

This guardian agreed to care for six orphans as well as her own baby.

Guardians

Another important task of volunteer counsellors is identifying and linking guardians with orphans. This is especially important since research (Rakai Community Based AIDS Project 2004) shows that the coping mechanisms of OVC are

enhanced by the presence of an adult in their life even if that adult is physically unable to care for them. Children are only matched with guardians if they do not have a family member who is able to care for them. Whenever possible, counsellors will collaborate with parents prior to their death to arrange a suitable guardian to ensure future care for their children. Some of the guardians already have families, but others do not. They usually live with the children. Most guardians are women because they are more likely to agree to shoulder the responsibility for caring for orphans and therefore are easier to recruit. Many guardians are in poor health and are themselves living with AIDS. Children often take over household duties and care for guardians who are living with AIDS when their health worsens so it's a mutually beneficial relationship. In fact, some guardians have even credited the children with saving their lives. PARDI estimates only about 27 per cent of the orphans it assists have guardians. Generally, only the youngest orphaned children are matched with guardians. This is primarily because there are too few guardians available to fill the need; however, there are some children, about 20 per cent of those PARDI supports, who refuse to have a guardian care for them because they fear they will be mistreated. In an effort to safeguard against mistreatment, counsellors only recruit guardians from within the community. They carefully monitor prospective guardians prior to recruiting them and after they assume responsibility for caring for children. Counsellors are instructed to report any problems or suspicions they have of mistreatment or abuse to PARDI supervisors.

A guardian comforts a child who recently lost both of his parents.

Health Outreach

Volunteer counsellors also help PARDI carry out its health outreach program by mobilizing the attendance of community members. PARDI offers the health outreach services in collaboration with the district health department. PARDI sets the time and venue for health outreach activities, the district provides a vehicle and health care professionals donate their services for free. There is still a cost associated for PARDI, however, as the CBO is required to pay for fuel and maintenance of the district vehicle for the duration it uses it. The program is offered on an ad hoc basis, depending on the availability of a district vehicle and health care professionals and whether PARDI has the required resources. A variety of services are offered, including health care check ups, basic first aid, and immunizations while more complicated cases are referred to the nearest

hospital. Some medication is available but only Panadol, a painkiller similar to Aspirin, is distributed for free. Health care professionals also counsel the community on how they can safeguard their health through simple measures such as boiling water, maintaining personal hygiene and cleaning pit latrines.

Networking helps maximize limited resources

Another priority for PARDI is networking with other CBOs and NGOs that are providing services to vulnerable people in Rakai district. To that end, PARDI is a member of Rakai Network for AIDS Service Organizations (RANASO) and Forum for NGOs in Rakai District (FONIRAD). These organizations allow PARDI to share information, experiences, and training. It allows PARDI to educate others about the needs of its clients and to keep abreast about the sort of services other organizations are providing and where their activities are taking place. This helps the organizations coordinate their activities so they avoid costly duplication. Through these networks, PARDI has access to valuable information from newsletters, publications and research surveys that can help the CBO carry out its work more effectively. Members of the networks often conduct joint training sessions, which help them build the capacity of their organizations more cost-effectively.

Another priority for PARDI is the continued growth and expansion of its network of contacts and partnerships with well-wishers from abroad, which is usually accomplished by chance encounters, making a deliberate effort to broaden awareness about the organization and the plight of the vulnerable people it supports whenever the opportunity arises and word of mouth. The CBO recruits most of its foreign volunteers this way[4]. For instance, PARDI hosted a volunteer from Japan at Samanya Orphanage Centre for a month, who, in turn, hosted a group of two dozen of so children from the centre's choir and drama group. Recently, PARDI met a representative from the United Nations Development Program, who assisted the CBO register with a United Nations Online Volunteer Program that provides professional services free of charge. PARDI has this brief meeting to credit for the upcoming launch of its new website at www.pardi.com, which is currently being constructed by a professional website designer in the United States. The UN is footing all of the

Photo courtesy of Ashinaga Rainbow House

Members of Samanya Orphanage Centre choir and drama group enjoy the company of a Japanese volunteer at Ashinaga Rainbow House in Kampala.

[4] My field practice was arranged as a result of just such an encounter with a student at Makerere University who often takes the opportunity to spread the word about PARDI with foreigners he meets on the Kampala campus.

bills associated with the construction and operation of the website. Under this same program, PARDI has also recruited an official spokesperson for the organization in the United States who is assisting with fundraising and resource mobilization. To that end, she has also launched a website at www.pardiusa.apictureaday.com.

Rights-based paradigm shift

PARDI is currently in the process of a paradigm shift in how it approaches programming, making a transition from a needs-based to a rights-based model of development and assistance. The shift is recognition, implicitly at least, of the failure of dominant modernization development practices to understand and address the structural barriers to poverty. Increasingly, instead, donors and NGOs are turning to a rights-based approach to development programming as a means of more systematically analyzing the causes of poverty, exclusion and marginalization. Thus, it is the donor and development community that is driving this paradigm shift, which presupposes that poor people are poor because they have been denied or have been unable to access rights and freedoms, which are necessary to living a dignified life.

PARDI staff compare the quality of drinking water at Samanya Orphanage Centre before and after a water tank (bottom photo) was constructed. According to the rights-based approach, children and orphanage volunteers forced to consume the water in the green cup were denied a basic human right.

It is believed the rights-based model has the potential to empower the poor and marginalized through strategies that enable them to recognize the rights they are entitled to such as the right to food, the right to health care, the right to shelter, and so on. Such strategies must address the basic needs of the most vulnerable, identify the political, economic, social and/or environmental conditions that create barriers to accessing rights, and provide mechanisms to overcome those barriers. These barriers can be related to the knowledge, skills and attitudes of those whose rights are denied as well as political, legal, administrative, social-cultural, economic and/or environmental in nature.

Internationally, the seminal human rights document is the International Bill of Right and this was later supplemented by other conventions and declarations, the most relevant for PARDI's work being the United Nations Convention on the Rights of the Child (UNCRC). Uganda is a signatory to both. Advocates of children's rights in Uganda can also draw on the Constitution of Uganda, the Uganda Children Act and other laws related to the rights of children. PARDI referred to the UNCRC and other relevant laws in November 2005 when it approached the Ugandan Human Rights Commission for assistance in lobbying and advocating on behalf of the children and other vulnerable people it supports. The organization was told the Commission would "look for easy access avenues to assist PARDI's beneficiaries enjoy their basic human rights," (personal communication, April 9, 2006). Key provisions of the UNCRC which can assist PARDI and other service providers, communities and policymakers in their efforts to assist children infected with and affected by AIDS, include:
Article 3: includes the provision that the best interests of the child shall be a primary consideration in matters concerning children
Article 5: recognizes the responsibility of the extended family, community or legal guardians to provide for children in a manner consistent with their evolving capacities
Article 8: addresses the right of children to preserve their own identity, including their name and family relations
Article 12: recognizes children's rights to be heard in any proceeding that concerns them
Article 18: recognizes the responsibility of the State to support parents and legal guardians in their child-rearing responsibilities and to develop services for the care of children
Article 19: concerns the protection of children from abuse, neglect, mistreatment or exploitation
Article 20: concerns the responsibility of the State to provide special protection for children deprived of their family environment
Article 21: addresses safeguards around adoption
Article 24: recognizes the right of children to the highest standard of health and access to health services
Article 25: concerns the periodic review of the situation of children placed in care
Article 27: recognizes the right of children to an adequate standard of living
Article 28: concerns the right of all children to education
Article 32: addresses the protection of children from economic exploitation
Article 34: asserts the right of children to protection from sexual exploitation and abuse.

IN THEIR WORDS, BY THEIR HANDS: The most pressing human security challenges of children affected by HIV/AIDS as revealed through their drawings, letters, skits and songs

"We are suffering because our parents died of AIDS."
Field research study respondent, Kooki county, Rakai district

An orphan participates in the research project.

The overall goal of a field research study conducted in January 2006 in Kooki county of Rakai district was to identify the most pressing human security challenges facing OVC assisted by PARDI in an effort to diagnose effective strategies to address those challenges. The study aimed to achieve the following objectives:

- To give participants the opportunity to express what it is like to be a child affected by AIDS through their personally conceived and created artwork
- To allow OVC to reveal their personal, subjective realities and experiences from their own perspective
- To use a medium that gives OVC the opportunity to express themselves directly
- To create a collection of artwork by OVC assisted by PARDI that could possibly be used as a future fundraiser for the organization

Paper and art supplies, consisting of pencil crayons, wax crayons, watercolour paints, pastels, and felt markers, were distributed to Samanya, Ntalama and Kijako orphanage centres. OVC who access services at the centres were extended an invitation to participate in the research project by conceiving and creating artwork using the paper and supplies that were provided. The children were given very few instructions, which were delivered to them in their own language by volunteer counsellors. AIDS has had a profound impact on the lives of all of the children who participated in the study and they simply were asked to use the medium to express their experiences, thoughts and feelings. The children who chose to participate had two or three days to conceive and create their artwork before it was collected at Samanya Orphanage Centre. Unfortunately, artwork from

Kijako orphanage centre was not made available by the conclusion of the study.

Since most of the children PARDI supports do not speak English, it is difficult to communicate with them without a translator. It was hoped that by choosing art as a medium for their self-expression, the children would have the opportunity to express what they think and how they feel about their unique circumstances as children affected by HIV/AIDS more directly. Many of the participants chose to express themselves in text written in their mother tongue, Luganda, with accompanying drawings. A plausible explanation for this is the OVC who participated in the study felt more comfortable describing their challenges in writing because they do not normally have access to art supplies and they aren't accustomed to expressing themselves using that kind of medium. For instance, none of the children chose to use the paints that were distributed because, according to one volunteer counsellor, no one knew how to use them.

Children create artwork for the project at Samanya Orphanage Centre.

A total of 157 responses were received from children ranging in age from four to 19. Eight-seven of the participants were female and 44 male. The sex of 26 of the respondents could not be determined. All of the survey participants chose to respond in written text. Seventy of the respondents wrote in Luganda[5], 54 in English and 33 in both Luganda and English. All but one of the respondents also included with their text at least one illustration, which they drew themselves or had a friend or sibling draw for them. Almost all of the drawings illustrate something mentioned in the text. Just over a third of the respondents drew real life scenarios and/or illustrations of people suffering some sort of distress. Five of the participants drew more sophisticated cartoon-like illustrations with callouts describing what a person in the illustration is thinking, feeling or saying.

Responses were consistent and similar in tone and content. All of the participants either identified or described significant human security challenges they confront on a regular basis and most stressed their struggle for basic necessities of survival and/or access to education. Table 3 indicates the needs and challenges expressed by the respondents. An overwhelming number of respondents lack bedding, bed sheets, blankets and a mattress to sleep on and over half lack clothing. Close to half do not have decent shelter. Some of the children reported living in temporary mud and grass-thatched homes that

[5] PARDI's Samuel Mukasa translated the Luganda text into English.

Table 3: Needs identified by OVC

NEED	NUMBER OF RESPONDENTS
Mattress/bedding/bed sheets/blanket	105
Clothing	88
Permanent/decent shelter	77
Scholastic materials/school supplies (books, pens, pencils)	58
School fees	50
Food	46
Shoes	31
School uniform	29
Mosquito net	25
Household items (soap, dishes, jerry can, wash basin, vaseline	21
Educational support	17
Land	17
Water tank	16
Hoe	5
Medicine	3
Latrine	3
Bicycle	3
Carpentry materials	3
Buildings/facilities for orphanage centre	3
Animals for rearing	2
Kitchen	2
Sewing machine for orphanage centre	2
Traditional musical instruments for orphanage centre	2
Public address system for orphanage centre	2
Sewing machine	1
Transport	1
Seeds	1
Granary	1
Mechanical equipment for vocational training at centre	1
Transportation for orphanage centre	1
Bicycle for orphanage centre	1
Lights for orphanage centre	1

leak and others said their homes were either had collapsed or were on the verge of collapsing. Almost a third of respondents said they do not get enough food to eat. Sixteen per cent do not have mosquito nets, 10 per cent do not have land for growing food and another 10 per cent would like a water tank because they have to walk such long distances to fetch water. Access to education is also a problem for the respondents. The Ugandan government introduced legislation in 1997 mandating universal primary education (UPE) and waiving school fees. But some children are still unable to attend because they can't afford scholastic materials and uniforms, which are required for them to go to school. Some respondents of the study described the specific items they lack which preclude them from attending school such as "school fees", "scholastic materials", which are supplies such as pens, pencils and books, school uniforms, and "school uniforms." Others simply expressed a need more generally for "educational support."

In addition to expressing their own needs, some of the respondents mentioned items needed by orphanage centres where they access services and receive support. "We don't have the necessary equipment, such as musical instruments, for our drama presentations in different areas when we are sensitizing the public about HIV/AIDS. We lack loud speakers, yet we perform to large gatherings. Another problem is lights. We don't have lamps. We would like to perform even at night. Another problem is that we don't have enough buildings. We would like to construct some more buildings at Samanya. We'd also like mechanical tools to repair motorcycles and bicycles. We are pleading to you to give us some bicycles because bicycles help us reach far when we want to spread information to our fellow members. Another problem is we don't have a vehicle to move us around when we are sensitizing the community about HIV/AIDS," explains a 15-year-old boy.

Many, such as the child who drew Illustration 1, included a drawing of the basic needs he lacks; and, others, like the boy who sketched Illustration 2, included his family in his illustration. In addition to expressing their needs, some of the children suggest that their situation is so "terrible" today is because they no longer have a mother or father. "We are so many orphans and we are still young. We are lacking parental care," writes one child. Another explains: "Our father died and even our mother died. They left us when we were still young and now we are in hands of counsellors. They act as our parents." Underneath the drawing of girl next to a small hut are the words: "This girl is an orphan who is living in this house alone." Another writes next to an illustration of eight children wielding hoes, "We are digging so that we can get food because our parents were lost long ago." Some of the children point out their parents sold the family's land and assets before they died, leaving the children with nothing.

Other children report that they are living with one parent or a relative who is

Illustration 1

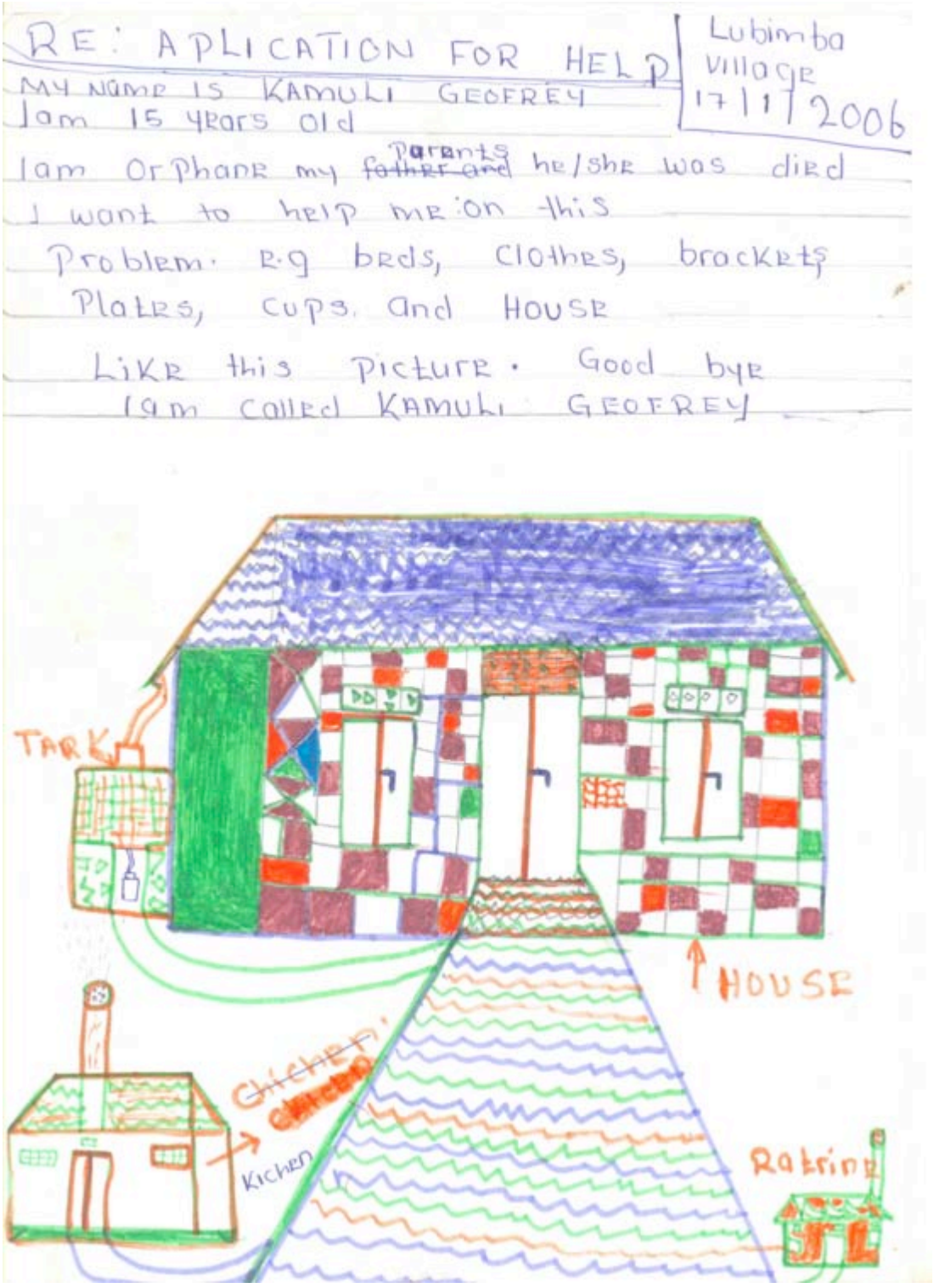


Illustration 2

having a difficult time supporting them because they are so impoverished, weak or elderly. Says one 14-year-old girl: “My dad died when I was very young. I don’t remember what he looks like and I’m the oldest in the family. My Mom is very weak and there are six in our family. We have no home. Our uncle assisted us by giving us a shack to live in, but now our uncle wants us to find our own home. But our mother lacks money and energy to build a house. Even if we had the money, we don’t have any land to put a house. We also have no food or clothes.” A 12-year-old girl explains, "Both of my parents are dead. By the time they died, we were left with nothing. We had no clothes or house. We live with our aunt, who is very poor.” Another girl illustrates her grandfather beating her grandmother with a stick. “They fight because of food,” she writes. In another illustration, a grandmother laments: “I’m so unfortunate. These orphans are so hungry yet I have no food. The house is ramshackled and it’s about to collapse. But I can’t build another house. The orphans have nothing to eat. I don’t

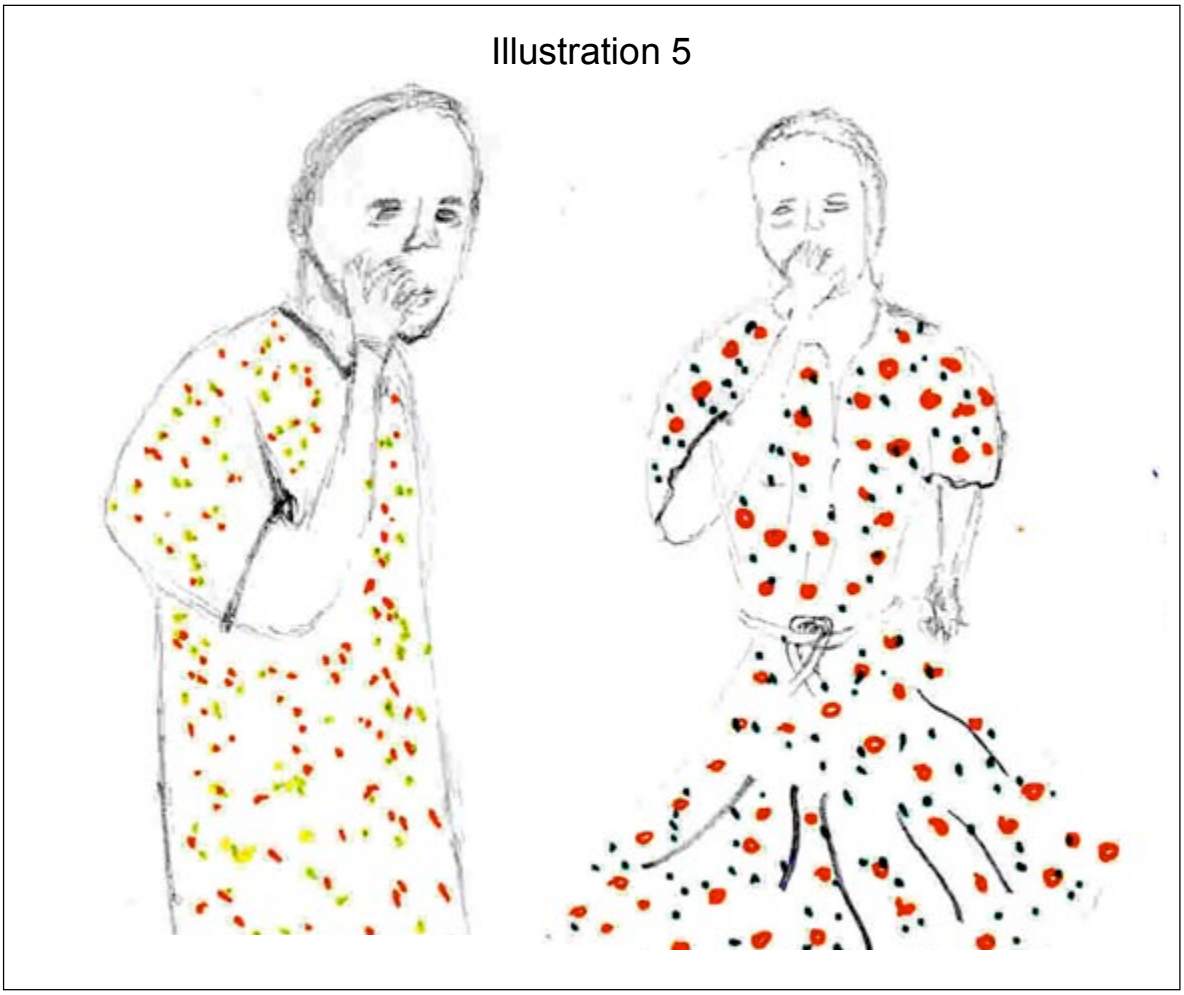
Illustration 3

have money for food and clothes. When it rains, we don't eat because the kitchen leaks and gets soaked with water. I'm asking for assistance because I can't manage. I'm dying because it's such a burden. I stopped the orphans from going to school so they could look for food to eat in the villages. Now, I'm asking for assistance because we sold off the piece of land we had to pay the medical expenses for the late parents. Now, the food we eat, it's the children who get it by asking for it from villagers."

Illustration 4

Other children, such as those who drew the pictures in Illustrations 3, 4 and 5, opted to use non-verbal gestures, specific to their culture, to convey what they need and how they feel. Illustration 3 signifies famine because the child in the drawing is too weak from hunger to lift her head. "We are facing famine. We want food. Famine is terrible in our family," says the 13-year-old girl who drew the picture. The girl in Illustration 4 has her arms stretched out with her palms facing upwards, which means she is appealing for help. The character at left in Illustration 5 is touching his face, which signifies he is feeling sorrow because he is remembering his

Illustration 5



deceased parents. The girl at right is covering her mouth with her hand, which indicates she is hungry and asking for food.

Some children, such as those who created Illustrations 6 and 7, chose to illustrate scenarios that PARDI staff confirms were likely inspired by real life events. The Luganda in Illustration 6 reads: "I'm an orphan both my parents

Illustration 6

died. Only the children remain and we don't have food." The 12-year-old boy who drew Illustration 7 says he "faced a lot of problem" after the death of his parents. "I stayed with my grandparents but they are very weak. After being dumped at my grandparents, I moved in with a guardian but the person who took me in is also very weak," he writes. The boy describes not only a variety of challenges facing people affected by HIV/AIDS but also what they think and how they feel about their problems. According to the text that accompanies the drawings in his illustration (below, from upper left corner), the boy in illustration is thinking: "My situation is very, very bad as if I'm the one responsible for killing my parents and other people." The elderly woman is thinking: "If I died now, who'd take care of my grandchildren." The elderly man at the bottom of the illustration says he feels as if he "has the weight of the world on his shoulders." He is also saying: "I hear there are people who assist orphans, Can they assist my grandchildren? This world can torture people." The call out underneath the illustration of the graveyard reads: "The earth has taken all of my family. My family has all disappeared in the soil. My father, mother, grandparents, brothers and sisters."

The children who drew Illustrations 8 and 9 focused on what they think they need to do to escape poverty and their desperate situations. The 17-year-old boy who drew Illustration 8 says he lost both his parents in 1994 and two of his

Illustration 7

brothers in 2003. “I finished P7 but I couldn’t continue to secondary school because I have no money. I see now my future is bleak. I see the world as if it is in a fog. I lack food. I wish I could go to vocational school to learn mechanics. I have no clothes, bed or bedding and no house,” he writes. The 14-year-old boy who created Illustration 9 says he also finished P7 and couldn’t afford to continue to secondary school. “I’m an orphan. Since I can’t afford school, I’d like to go to vocational school to learn how to repair motor vehicles and motorcycles. I have no house. The house I stay in is very poor. I have no bed and beddings and clothing. We lack basic necessities like soap, salt and food. We also need a bicycle to fetch water and to carry sick loved ones to the hospital. If I were to become a mechanic I could be self-reliant and support myself and my siblings in the future.”

Illustration 8

Illustration 9

The child who drew Illustration 10 also makes reference to the difference learning a skill would make in the life of an OVC. According to the text that accompanies the illustration, the artist also describes some of the human security challenges facing people affected by HIV/AIDS as well as what they think and how they feel about their circumstances. Clockwise from top left:
The man smoking the pipe is saying, “Ladies and gentlemen I smoke this pipe to reduce my worries about the famine and I’m dying of hunger.”
The woman with he pink skirt is saying, “My kids abandoned me yet I’m old and sickly and my house is about to fall down on me. I am also famine-stricken so I seek assistance.”
The two characters around the cooking stove are saying, “Help us, we don’t have anything to eat. We go to sleep hungry. All we have to eat is bananas that are not meant to be eaten, but they are used to make wine.”
The character on the purple bed is saying, “Friends I’m dying. HIV is killing me. I got it from my mother and I have no support.

Illustration 10

The child with orange shorts and the yellow shirt is crying with outstretched hands and saying, “Friends, my parents died of HIV/AIDS. I don’t have any food so assist me.”
The man with the purple shirt, green pants and batch of bananas is thinking, “I don’t have money to pay school fees for my children so let them stay at home. Meanwhile, I’m looking for money in the village.”
The woman with the pink dress sitting on the stool is thinking, “I’m so badly off. Had I known how to sew, I think I’d be able to sustain myself.”

AIDS education through music and drama

Innovative performance arts groups, which educate through music, drama and dance, are among the most creative cultural responses to the AIDS epidemic at the community level in Uganda. Choir and drama groups, made up of OVC who access orphanage centres, are an extremely important component of PARDI’s overall HIV/AIDS prevention strategy and its efforts to reduce the stigma, isolation and discrimination associated with the virus. The groups give OVC a powerful artistic tool to broaden awareness about their unique challenges and to express how they feel to be children affected by HIV/AIDS. They also are an excellent opportunity for OVC to learn about HIV and AIDS and the children, in turn, help to educate others about the virus through ongoing community performances of their songs and skits. Like other prevention programs, the children’s songs and dramatic skits are designed to dispel popular myths and misperceptions about HIV/AIDS while disseminating accurate information about the virus, the disease and its transmission. They also identify high risk factors for HIV and encourage behavioural change to minimize the risk of contracting the virus.

Children from Samanya Orphanage Centre drama group perform a skit that dramatizes the effect of the HIV virus on the body

The children’s performances are highly accessible, engaging and entertaining because they are created, in a culturally-contextualized fashion, specifically for a target audience. Put another way, the children’s songs and scripts are relevant, appropriate and suitable because they are designed for the community by community members who are intimately familiar with the culture. Even though the subject matter can be grave and even gut wrenching at times the performances are infused with humour so audiences can enjoy themselves as they reflect on what are often difficult and painful issues. Counsellors, in collaboration with child

performers, compose the lyrics and scripts. The songs are accompanied by traditional drumming, which has been passed down from generation to generation.

The children's skits dramatize how the virus attacks the body's immune system, the physiological effects the disease has on the body, and the devastating impact the epidemic has on families. The performances stress abstinence, monogamy and the use of condoms to prevent the spread of HIV/AIDS. The performers also demonstrate what PWAs need to do to prolong their lives such as eating a healthy diet, taking medications for opportunistic infections (OIs), keeping a positive attitude and talking openly about their illness.

Samanya drama group actors mourn the loss death of another character from AIDS.

In addition to curbing the spread of HIV, the drama and choir groups promote the emotional and psycho-social well-being of children who participate in them. Being part of the drama and choir groups boosts the children's self-esteem, enables OVC to explore their fears and anxieties in a constructive way, and allows them to sensitize the community about the unique challenges they face, including their susceptibility to abuse, exploitation and discrimination. Issues such as property grabbing, mistreatment of orphans by guardians and relatives, access to education, and girls being pressured into early marriages or the sex trade to help support themselves or their families are some of the themes explored in the skits and songs. Listed below are three songs and two scripts performed regularly by Samanya Orphanage Centre's Drama and Choir Group[6]. (The three songs and a couple of short clips of one of the group's skits are included on the CD that accompanies this report).

Song No 1: You Never Know I Might Also Fall Victim (Osanga Nange Alintwala)

Chorus (repeated twice)
There's wailing and weeping from every corner
What AIDS has done to us is really frightening
You never know, I might also fall victim

We have buried many young children and youth and

[6] Dr. Nyanzi Ismail, a lecturer in the Language Department at Makerere University and a Ugandan linguistic expert, was commissioned by the author to translate the songs and skits into Engliish. The Luganda text is included in Appendix C: Field Activities, pages 95-96.

We are losing hope
You never know, I might also fall a victim
(Chorus)

Please utilise the female and male condoms, they are very effective once used correctly, that way you will overcome AIDS
Young people, widows and orphans get to live a very short life span before they are also carried away by the scourge
(Chorus)

A singer from Samanya choir performs a song that urges listeners to change risky behaviours.

You should learn to avoid bad-risky influences like all-night discos, prostitution, pornographic films and drunkedness because they contribute to the spreading of HIV and AIDS
Avoid sharing sharp instruments like needles and razor blades
(Chorus)

You should not engage in sexual relations with your partner before going for an HIV test because you can never know what could happen
(Chorus)

As I bid you farewell, I request you to put everything I have said into action such that HIV and AIDS does not rob us of our lives
(Chorus)

Song No 2: The Scourge Came For Us All!
(Wowe Yaye Na Twagirwa)

Chorus (repeated twice)
Goodness, AIDS came to finish us from the earth, the elderly, youth and babies have all been snatched away. The solution to this would be to return to God. He is very angry with us

Did you know that AIDS came very determined to wipe out the whole earth
AIDS built a permanent house called 'abstinence' with a caretaker as the angel of death? So once you decide to enter that house, you will come face to face with him
(Chorus)

A saying goes that the tree seedlings are the future of a forest but our youths and babies

Samanya choir members use their music as a healing tool, to come to terms with their grief.

have all died, we are wondering where tomorrow's citizens will come from.
(Chorus)

Let us join hands; let's change our behaviours especially through abstinence.
(Chorus)

Song No 3: What Crime Did We Commit As Children? (Ffe Abato Twaza Sango Kii Elyo?)

Chorus (repeated twice)
What kind of crime did we commit, which has tortured our lives to the extent of having no peace

We are raped by men
(Chorus)

Traditional healers sacrifice us
(Chorus)

Our mothers throw us in pit latrines
(Chorus)

Our parents throw us along the roads
(Chorus)

Samanya choir sensitizes others about the problems of OVC.

Play No 1

Scene 1: A boy meets his friend whom he convinces to take some alcohol. They then go to a bar where they find prostitutes selling alcohol.

Scene 2: They buy the alcohol and sit around with prostitutes sipping some drinks. They later on, pay the prostitutes and have sex with them. One of the boys comes back on the stage with fever and itching all over his body.

Samanya actors dramatize how witch doctors and traditional healers sometimes take advantage of people infected with HIV.

Scene 3: His friends find him later and they assure him that he's been the target of witchcraft. They take him to a traditional healer who is also on the stage. He informs them that he will inject the patient and administer medicine through body cuts. He asks for payment of a white goat, white clothing and 200,000 USh.

Scene 4: The patient goes home to sell a plot of land in order to get the money for the witch doctor. But his health worsens and later he and his friends, who seek help from the witch doctor, die.

Note: *This play shows how HIV and AIDS rapidly spreads among people in the rural communities of Uganda who are uninformed about the epidemic.*

Play No 2

Scene 1: A man marries a woman who gives birth to a baby girl. This woman later dies. The husband marries another woman who also gives birth to a child. The orphan falls prey to torture by her stepmother. This orphan is overworked by the stepmother.

Scene 2: The poor orphan decides to run away from home but meets a man along the way who rapes her and infects her with AIDS. She later dies.

Note: *This play involves a lot of domestic chores which the orphans go through that are forced on to them by their guardians and later they fall victims of HIV and AIDS.*

The actor second from left plays a character who contracts HIV after leaving her home due to mistreatment.

Song Immediately after play

Oh my God, we have fallen victim to this incurable disease. HIV/AIDS, this epidemic tortures people both young and old. It has also greatly hindered development.

We had a variety of diseases. Where are they now? Syphilis and polio among others, but many of them came and were wiped away. But whoever opened the door for this scourge has never closed it.

CHILDREN IN JEOPARY:
The impact of HIV/AIDS on children

I cannot deny the fact that I am infected and soon AIDS is claiming me. But the future of my children haunts me because no one will cater for them.

Words, spoken within weeks of her death, of a 21-year-old mother of two who was forced by relatives into marriage, at age 14, with an abusive man who previously had lost three wives to AIDS, Kabula county, Rakai district

If I do not beg … I offer my labour in exchange for food but most of the time I survive on water."

Eight-year-old boy who has since died, Kabula county, Rakai district

All we need is land for cultivation, meals, clothes, a decent house, and stationary for my brothers who attend school.

18-year-old boy who lost his mother in 1993 and has looked after his three brothers and sister since the death of his father in 1998, Kooki county, Rakai district

Maama, come out. We are hungry. We want food.

Cries of three-year-old twins James and John to the grave of their mother, Kooki county, Rakai district

Children and youth in Africa are at the frontline: the most vulnerable to HIV/AIDS not just in terms of infection, but in taking the brunt of the epidemic.

UNAIDS (2000b: 13)

As the field research study detailed in the previous section and case studies presented in this section reveal, HIV/AIDS has a profound impact on the well-being of children. Like millions of children in sub-Saharan nations, who "are missing parents, siblings, schooling, health care, basic protection and many of the other fundamentals of childhood because of the toll the disease is taking" (UNICEF 2005), OVC in the counties where PARDI operates are vulnerable in most areas of their lives. For most of these children, survival is all-consuming struggle, dwarfing everything else. OVC, as well as their parents and the guardians who care for them, are preoccupied most especially with meeting their most basic necessities of survival — adequate shelter, bedding to sleep comfortably at night, food, clothing, safe drinking water — as well as being able to go to school, according to the field research study and prior research (Gilborn, Nyonyintono, Kambumbuli and Jagwe-Wadda 2001; Rakai Community-based AIDS Project 2004; Shuey et. al 1996: Foster et. al 1995; Foster et. al 1997; Hunter and Williamson 1998; Hunter and Williamson 2000). Addressing these needs, in turn, is important not only for their physical health, it is also critical to the emotional, psycho-social, and spiritual well-being of children.

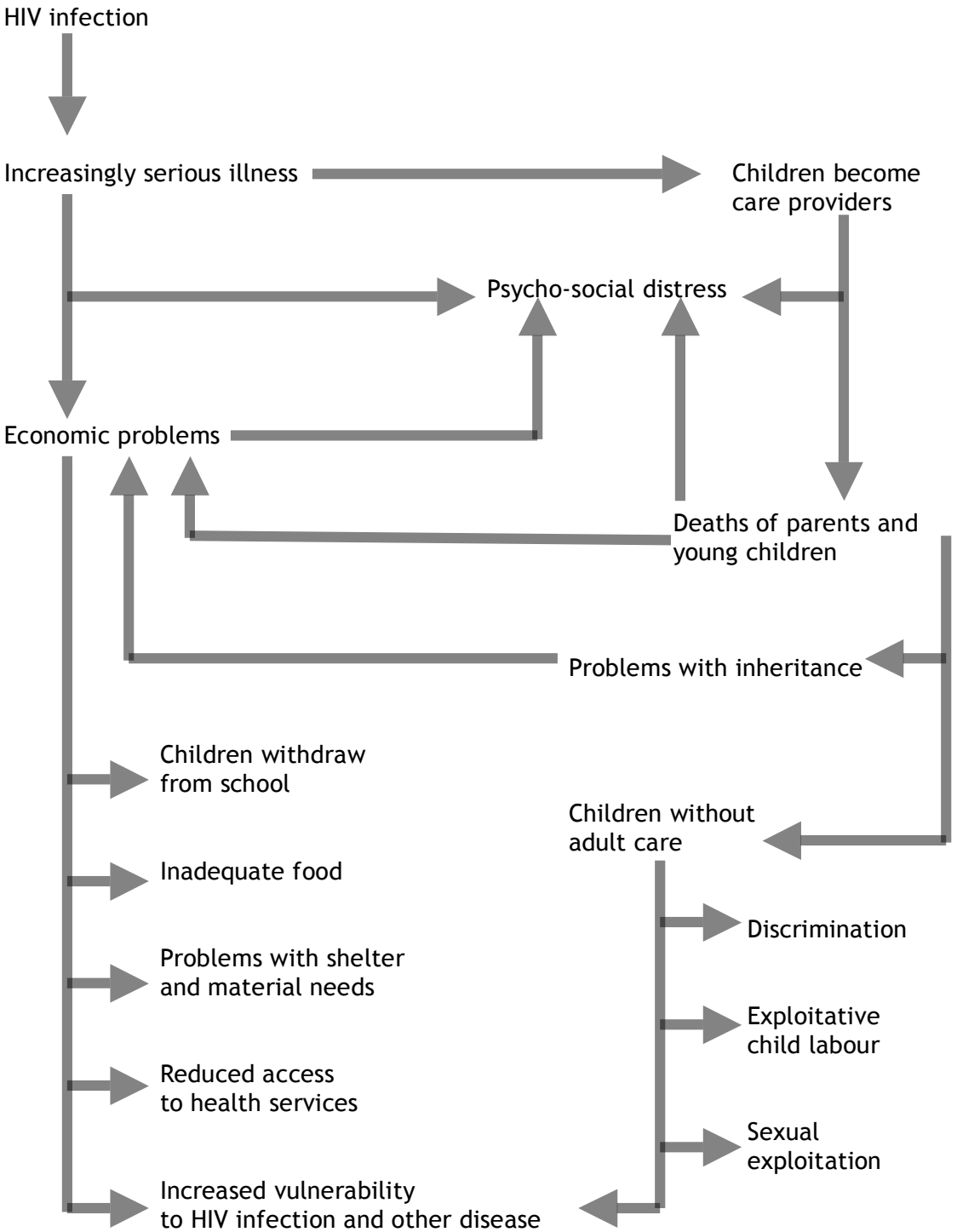
Since OVC are unable to meet their basic needs themselves, traditional coping mechanisms and community-based organizations like PARDI are too overstretched to assist every child in need, and OVC receive little or no support or services from government agencies and other NGOs, many of their needs go unmet. A 2004 study in Rakai district found that almost half of all CHHs receive no support from NGOs or government agencies (Rakai Community-based AIDS Project 2004: 59). Jackson (2002: 258-259), notes that "as the epidemic unfolded in sub-Saharan Africa in the 1980s and 1990s, the impact on children initially was not given priority, except within communities who quietly and largely unassisted, took care of orphaned children." Instead, she adds, funds from donors, governments and nongovernmental organizations were channelled into HIV awareness and prevention programs and overburdened home-care services; the needs of children affected by AIDS, particularly the so-called "orphan generation", remained largely hidden within the community.

Despite the efforts of some community members to assist children affected by AIDS, there are also cultural reasons why children are not receiving support they need, according to Milly Baiga Katongole, HIV/AIDS coordinator for Concern's Rakai Program. "In African culture, children are seen as valuable only after they are grown up … and attitude of some, [particularly with regard to HIV-positive children is], we're wasting our time looking after children because they are going to die anyway." Nationally, she adds, OVC "are considered a problem of NGOs, but no one thinks of it as a government problem. The needs of children are always considered last" (personal communication, Oct. 12, 2005).

Last fall, UNICEF and UNAIDS admitted that children affected by AIDS have been missing from global and national policy discussions on HIV/AIDS and an overwhelming majority, over 90 per cent, of children orphaned and made vulnerable by the disease do not receive public support or services. To address this shortcoming, the two UN organizations launched "Unite for Children, Unite Against AIDS", a global campaign focusing on the enormous impact of HIV/AIDS on children and they are advocating for funding to be specifically targeted for children affected by AIDS. Unless this happens, an increasing number of OVC in Uganda generally and Rakai district in particular will be forced to live in unimaginable destitution and deprivation because the number of orphans is only expected to grow because. According to experts "orphanhood peaks seven to 10 years after the peaks in HIV seroprevalence occur" (Gilborn, Nyonyintono, Kambumbuli and Jagwe-Wadda 2001: 3).

Besides a relentless struggle for the basic necessities of survival, OVC face other interlocking challenges — reduced access to education, psycho-social distress, discrimination and mistreatment by guardians and relatives, limited access to health care, and increased vulnerability to HIV infection and other

Figure 1: Human Security Challenges
Facing Children and Families Affected by HIV/AIDS



Source: Williamson in Levine and Foster (2000:25)

disease. Figure 1 shows how these human security challenges are interconnected.

OVC demonstrate incredible resourcefulness, creativity and resilience in coping with their challenges, but often the demands of daily life mean they must sacrifice one of the things they value the most — an education. PARDI estimates that approximately 60 per cent of the children it assists attend school. But that figure fluctuates depending on the children's availability of food and scholastic materials. Besides an inability to pay for school fees and scholastic materials, other factors also prevent OVC from attending school. Some are forced to withdraw from school because they are pressed into service at home, taking care of siblings or a sick parent or guardian. One 12-year-old boy study, revealed to PARDI field workers the difficulty he has managing school along with his other responsibilities, including caring for his 75-year-old grandmother. "I have to go to school every day but also look for food and other household needs. I really want to study but the sickness of my grandmother cannot allow me. I have to prepare for her everything before I go away. But as she starts crying whenever she notices I am moving away, I feel touched and decide to stay. She looked after me from childhood, and I cannot neglect her at this crucial moment."

Others quit school so they can provide for their family. Many children till their neighbours' land in exchange for meager pay or food; others sell fruit, firewood or crafts. A 17-year-old boy, who became the head of a household of four at the age of 12 after both his parents died of AIDS, told PARDI field workers he quit school in P6 so he could focus on raising his two brothers and sister and to give them a chance for an education. "When our parents died, I thought of going to Kampala and living on the street, but I had a second thought that I would be crucifying my brothers and sister given the fact that I am their only immediate relative," he told PARDI field workers. To support the family, the boy makes ropes and rears goats, the proceeds from which he says will be used to educate his brothers. Some children are too busy with household chores to spare the time it takes to walk the long distances to school and girls, in particular, leave school due to early marriages or pregnancies.

Besides improving their long-term security through increased incomes, getting an education also seems to be linked to the emotional and psycho-social well-being of OVCs as well as their parents and guardians. Said one 10-year-old girl respondent of the field research study: "If I were to go to school, everything would be OK. If one day I woke up and I was going to school, I'd be very, very happy and I'd forgot the sorrow I feel by the death of my parents." Her sentiments echo an earlier study in two other districts of Uganda that asked OVC what made them happy. Invariably, the responses were "being in school" and "being with other children … conversely, missing school and doing poorly in school [were] associated with feelings of sadness and social isolation" (Gilborn, Nyonyintono, Kambumbuli and Jagwe-Wadda 2001: 18). The same study (2001:

11) found that limited access to education is a source of psycho-social distress for parents and guardians of OVC, it follows that they would feel some peace of mind in the knowledge that their children receive an education.

PARDI reports confirm previous research in Rakai district (Nalugoda 1997; Sengendo and Nimbi 1997) that some orphans are discriminated against and sometimes suffer physical and verbal abuse from guardians and relatives who care for them. Orphaned children tend to have poorer clothing, are less well fed, and are required to do more household chores than the natural children of their caregivers. Some orphans are denied an education even as the biological children of caregivers go to school. A 12-year-old boy told PARDI staff he was made to take care of goats, tend to crops, and walk long distances to collect water after he moved in with his aunt and uncle. The child said his aunt, in particular, "treated him as an outsider" and when his cousins misbehaved he was blamed and brutally beaten by his uncle. After one such beating, the boy suffered a serious wound to his forehead but was still forced to carry a 10L jerry can of water on his head. "He was stressed to the extent he doesn't love himself anymore," says Hagaba Richard (personal communication, March 29, 2006). Some-times these children flee these homes to seek work in urban centres or they opt to live alone or with siblings in a CHH.

Other OVC, primarily girls, are lured into early marriages especially to older men not by choice but as a means of survival. As one 63-year-old fretted to PARDI field workers of her 10-year-old granddaughter, "I am wondering about Agnes' future since she is still too young to get married, probably it would solve her problems. Other girls are exposed to sexual exploitation as child prostitutes and both girls and boys often encounter economic exploitation domestic servants or child labourers. It's not uncommon, for instance, for them to refuse to pay children for their services. "We are joining hands in participating in a number of activities to earn a living," a 16-year-old boy living in a child-headed household told PARDI field workers. "However, in return we are not paid. This is very discouraging."

Another problem facing orphaned children is property grabbing, whereby inherited property is stolen from the surviving family members and heirs to whom it rightfully belongs. PARDI staff says this phenomenon is quite common and research conducted in two other districts of Uganda (Rakai Community-based AIDS Project 2004; Gilborn, Nyonyintono, Kambumbuli and Jagwe-Wadda 2001) suggests property grabbing is widespread, with women and children especially vulnerable. Paternal relatives are thought to be the most likely to steal inherited property, but there are also some fears that other community members and maternal relatives will do so. Since land is the most important survival resource for OVC, this is a serious matter because it further undermines the livelihood of households that are already weakened by the death of the primary income-generator.

Like other impoverished children in sub-Saharan Africa, OVC affected by HIV/AIDS have limited access to health care, and increased vulnerability to HIV infection and other diseases. It is impossible to say with absolute certainty just how many of the children PARDI supports are HIV-positive because a lack of resources precludes most from being tested. In fact, the CBO estimates that only about 10 per cent of the children it assists are tested for the virus. But according to Jackson (2002: 268), "most children orphaned by AIDS do not have HIV because few children born with HIV outlive their parents. As the rate of transmission from mother to child is reduced, even fewer children who are orphaned will be infected." Still, analysts believe OVC are at high risk of contracting HIV/AIDS as they grow up and "female orphans are more at risk of infection than any other group in the population" (Gilborn, Nyonyintono, Kambumbuli and Jagwe-Wadda 2001: 4).

Lost childhoods – how children cope in CHHs[7]

Eight-year-old Nkwasibwe Marion crouches by her dying father's bedside. She peers anxiously into her father's eyes and gently takes his outstretched hand. Tenderly, she grasps the soiled, cotton bed sheet and wool blanket that are keeping her father warm and begins to pull them over his emaciated body.

Nkwasibwe Marion cares for her dying father Katula Charles.

But sensing he has a visitor, Katula Charles interrupts her. He struggles to steady himself on one elbow and moans, a series of agonizing groans that sound as if they are emanating from deep within his abdomen. He gasps for air and grimaces in pain as he props himself up on his thin foam mattress. His ribs protrude sharply from his gaunt, desiccated abdomen.

Although he is only 42 years old, he looks to be almost twice that age. The merciless disease, commonly known in Uganda as "slim" because of the wasting effect it has on the body, is visibly destroying him. He coughs violently; his hands shake as he labours to dab the spittle from his lips with his sheet. He slowly turns to see the stranger who has entered his tiny mud and grass thatched home, weakly shakes the hand that has been extended to him and nods his head in acknowledgment. But his eyes are hollow and vacant; he says nothing. He is too weak to utter even a single word.

[7] This case study was featured on CBC.ca.

Drawing down savings, selling off assets

Katula Charles discovered he had AIDS three years ago when his second wife died from the disease. He sold his livestock and most of his land to cover the costs to travel several kilometres once a week to the local health clinic. There, he received treatment and medication, free of charge, for opportunistic diseases that are known to exploit bodies with weakened immune systems such as pneumonia, tuberculosis, bacterial and fungal infections.

Katula Charles relies entirely on his children for his care.

He pleaded with his health-care workers to allow him to reduce the frequency of his visits to the clinic to every two weeks to cut down on his transportation bill. But when his funds eventually dried up, there was nothing he could do but remain at home and his condition deteriorated rapidly.

He couldn't afford to pay the fee for antiretroviral drugs, which have dramatically reduced AIDS and AIDS-related deaths in developed countries like Canada. But even if he'd had access to the costly medication, it might not have helped him. Some medical experts contend antiretroviral treatment cannot be effectively prescribed for people whose primary health and nutritional needs are not being met. To put it another way, if ART is to be effective in prolonging the lives of PLA in Uganda and the rest of Africa, there must first be significant reductions in poverty, improvements to nutrition, increased food security, secure livelihoods, increased access to primary health care and a basic quality of life.

On the dirt floor beside Katula Charles's bed are remnants of a meal of watery rice in a blue plastic cup; a filthy discarded salad dressing container serves as a makeshift water jug. Now bedridden, Katula Charles is completely dependant on his young children for his care. His oldest child, Nkwasibwe Marion, has become the de facto head of the household.

Survival is a struggle

Outside, seven-year-old Sentongo Abel has lit a fire and carefully deposited about 100 grains of rice into a pot to prepare another meal of rice for his father while his older sister carves up a single mango. The children used to cook their food on a flame inside their home, but fearing their father would suffocate from the smoke, they decided to move the fire pit outside.

Once their father's needs are taken care of, the children will feast on a bunch of green bananas that were given to them by a local farmer who took pity on them. Generally, the particular variety of bananas the children have been given isn't eaten; rather, it is brewed into wine. But that doesn't seem to bother them. They are happy to have even one meal to eat today.

Nkwasibwe Marion, Sentongo Abel and Muhezi Fransis are clearly devoted to their father and they are committed to doing what they can to relieve his suffering even though they are only eight, seven and five years of age, respectively. In addition to the trauma of seeing their parents die, they bear the brunt of striving to cope materially. Still, they enthusiastically demonstrate the chores they each must do in order for their family to survive.

Sentongo Abel, top photo, cooks lunch for his father and, photo below , demonstrates how he fetches papaya

Nkwasibwe Marion plops a yellow jerry can on her head to show how she fetches water. She makes the four-hour trip almost every day to a community water source that is shared with free-range livestock. Sentongo Abel jumps on the trunk of one of the family's papaya trees, and shimmies up and down to show how he picks the fruit. Little Muhezi Fransis wields a hoe and skillfully removes weeds to demonstrate how he tends to the family garden.

During the rainy season, the children often endure sleepless nights because water pours in on them through the holes in their grass-thatched roof. As their father is confined to the family's only mattress and he uses all of the family's bedding, the children must gather coarse, dried banana leaves from their garden to sleep on each night and they have only the clothes on their backs for warmth.

Although they do their best to cultivate their small plot of land, they lack the manpower required to reap a substantial yield from the unproductive land. Their stunted growth, reed-thin limbs and swollen bellies disclose malnutrition and chronic worm and parasitic infections.

Caring for their dying father keeps the children out of school but an education is also a luxury they cannot afford for they lack the money to purchase school uniforms and scholastic materials such as pens, pencils, notebooks, textbooks and mathematical sets. Loss of schooling has profound implications for the children's futures. Without an education, Nkwasibwe Marion, Sentongo Abel, and Muhezi Fransis will have a difficult time securing work when they grow up and for Marion there is an increased risk she'll be forced into the sex trade to survive.

Bleak futures

Their blank, stoic expressions conceal a lifetime of hopelessness, helplessness and despair, a relentless and perpetual preoccupation with immediate survival needs, a wretched existence devoid of even the most basic human joys. "I feel so burdened. I have no hope. Dad is dying and I am completely unable to save his life," says Nkwasibwe Marion, wiping tears from her eyes. At the tender age of eight, she has become the de facto head of her household.

She and her brothers have been denied the basic closeness of family life. They've never known what it is to feel love, attention and affection. "Ever since my mother died, I have never been happy like other children with parents who love and care for them. I only feel pain and hunger," says Sentongo Abel.

Their paternal aunt checks in on the family every now and then, but she is an impoverished single mother who is struggling to care for her own children. Besides emotional support and periodic palliative care for her brother, she can offer nothing more to the family.

Katula Charles is acutely aware that his children face an uncertain and bleak future. He pleads with a PARDI field worker who has dropped in on the family: "Please, please … I'm dying. My children. Help my children," he says before collapsing on his bed. His desperate deathbed appeal has left him completely spent.
(Note: *Katula Charles died on Dec 4, 2005, after this case study was written. His children now live with a guardian who PARDI arranged to have care for them.)*

No respite: Grandparents shoulder responsibility for care

Nalongo Josephine, 70, cares for two girls and five boys who were orphaned following the death of Nalongo's sons, daughters and brothers. The children are fortunate enough to attend a nearby school for free, under Uganda's Universal Primary Education program in which students are not required to pay school fees, but they must cover the costs of their school uniforms and school supplies.

Nalongo Josephine cares for seven orphans.

Nalongo earns money selling cooked cattle hooves in a nearby market, but she doesn't make nearly enough to support her large family. She also rears two young goats, which she expects to sell when they are fully grown to supplement the family income. The family usually eats only one meal a day consisting of posho (a Ugandan food staple made from maize flour) and vegetables because they cannot afford meat.

After the collapse of their poorly constructed brick home, the family was forced to move into a tiny grass thatched house. The family has no bedding, and they are forced to sleep on the dirt floor. Large cracks in the walls of the home make the family an easy target for mosquitoes and increases their risk of contracting malaria. Like other families affected by AIDS, Nalongo Josephine and her children lack the basic necessities to live a decent life. Despite all the hardship, Kyolaba, the eldest girl in the family has aspirations of one day becoming a doctor.

Nakiwala Federes and her six grandchildren sometimes go without food.

Basic necessities hard to come by

Despite her wretched living conditions, Nakiwala Federes chuckles before revealing she isn't quite sure how old she is, although she is certain she is over 80 years of age. She has been caring for her six grandchildren for eight years ever since her own two children died of AIDS.

The family is lucky to eat one meal a day and some days they are forced to go without food. In exchange for food, the children often provide casual labour in their neighbour's gardens. But such work is hard to find. The family has no latrine or kitchen. Even though it poses a serious fire risk, the family's kitchen

consists of a fire pit inside their grass thatched home. The children cannot afford the scholastic materials or school uniforms necessary to go to school and even if they could they would be unable to walk the long distance to the nearest school.

Four years ago, Nakiwala Federes says her hopes were buoyed after a visit from a member of an international humanitarian NGO, who promised to construct a new home for the family. But no one from the organization ever returned and her hopes have been dashed. In addition to food, clothing and bedding, the family requires improved shelter, including a kitchen, latrine, and domestic water tank as well as funds so the children can attend school.

Like other hard-hit areas of Africa, many AIDS orphans in Rakai district are cared for by elderly grandparents, which exacerbates an already tenuous situation because their own poverty, advanced age and/or ill health make them ill equipped to property care for the children. Nakiwala Federes worries about what will happen to the children after she dies.

Basic needs go unmet

Many of the OVC and vulnerable people PARDI assists are deprived of the basic needs for survival, including adequate shelter, food and clothing.

Many homes leak, such as the grass thatched homes above and top left. During heavy rains, the inhabitants get very little sleep at night and some have to “stand just like poles.” Others are on the verge of collapse or they have already collapsed, like the home at left. Almost all of the homes lack latrines and kitchens. They also lack blankets and bedding and as a result sleep very poorly.

Many OVC are malnourished due to seasonal fluctuations in food supplies. The worst off sometimes eat only two meals a weak. Children often beg for food or do odd jobs in exchange for food. Many OVC do not have adequate clothing and are forced to wear rags such as the children at right. In addition to being malnourished, many have hookworms, which exacerbates their malnourishment and causes their stomachs to swell, such as the girl at far right.

Access to safe drinking water is also a significant problem for OVC. Some children have to walk great distances fetch water from a poor quality source that is shared with free-range livestock and other animals.

For as long as he can remember, Kiiza Emmanuel (in photos on previous page) has been fetching water from a very dirty water source that he shares with approximately 3,000 neighbours and their free-range cattle. The 12-year-old boy, who lost his father to AIDS, lives with his mother who is very weak. He and his family of five use the water for cooking, drinking and bathing. Often Kiiza carries two 10L jerry cans of water the two-kilometre trek to his family home. During the dry season when the watering hole dries up, the family really suffers, he says. The family then must purchase piped water for 1,000 USh per jerry can from a heath centre located about a kilometre up the road from the watering hole, which is hooked up to the Lyantonde town water system. Since the family cannot afford the expense of the water, their water use drops dramatically during the dry season. Eight-year-old Nkwasibwe Marion, right, is too poor to buy a bicycle. She carries the 10L jerry can on her head the four-hour hike to fetch water. When collecting water is such an arduous, time-consuming process, hygiene suffers. As one eight-year-old boy once commented to PARDI staff, “I can take some eight months without bathing or washing. Do not think that I do not want to bathe but for sure water is got from very far…”

CONCLUSION:
Lessons learned and the recommended way forward

As they have done throughout the AIDS epidemic, communities will rise to confront the challenges they face and will struggle to do what needs to be done. They should not have to struggle alone. They should be recognized as full partners and supported in a united effort to reduce the tragic and unnecessary deaths and suffering caused by this epidemic, and by the glaring inequities in health care and treatment throughout the world.

Dr. Purnima Man, Director of Policy, Evidence and Partnerships, UNAIDS, July 2005 (UNAIDS 2005: 7)

Caring properly and fully for children today is the best investment a nation can make for national stability and prosperity tomorrow. Such care, ensuring physical, emotional, social, educational and material well-being is as essential for HIV prevention as it is for long-term social stability and development, and to meet the basic human rights of the children concerned.

Jackson (2002: 277)

My heart bleeds to watch innocent children suffer helplessly. This is the most forgotten human tragedy.

Nakiseka Josephine, 12, an orphan of Samanya orphanage centre[8]

We seek support and let us all pay attention like we did for the victims of the tsunami disaster and the crisis in Darfur in Sudan. That's all we ask. We believe we can all do something to change the situation in Rakai, Uganda.

Orphans at Samanya orphanage centre led by Namugunya Jospehine

No child in this country needs to go through this experience of prolonged sickness, starvation, and eventually premature death. It is a shame some people have watched not hundreds but thousands of helpless children in Rakai silently go through this suffering.

Ahimbisibwe David, 13, an orphan from Kalagala orphanage centre

Let's claim children as "zones of hope". In this way, mankind will declare that a decent childhood is not a distant memory and that all children must be protected from the pernicious impacts of the HIV/AIDS disaster... Hope and happiness is every child's desire.

Nankinga Fiona, 10, an orphan from Samanya orphanage centre

I'd been working with PARDI several months before the sheer magnitude of the HIV/AIDS epidemic in Rakai district hit me as if all of the rich red dirt from all of the holes dug to bury the dead was suddenly dumped on me. At the funeral service and burial of the disease's latest victim, neighbours gingerly lowered a

[8] Quotations from these OVC were translated from Luganda to English by PARDI staff.

wooden box containing a 42-year-old peasant farmer into the ground behind his tiny mud house. After reciting several passages from the Bible, a Catholic priest delicately filled a shovel with dirt and scattered it into the hole. Dozens of villagers quickly finished the job the clergyman had started. With quiet, dignified determination, they handed off their hoes like batons in a relay, each, in turn, sharing responsibility for filling in the grave of their lost friend. A flurry of women then led the victim's nine-year-old daughter in a circle around the mound of earth, using their fingers like tiny excavators, scooping up dirt and sprinkling it on the grave. Some last minute adjustments to a cross — two wooden sticks tied together with some banana fibre — were done before it was pressed firmly into the head of the grave signaling the end of the service.

A Catholic priest scatters dirt on the grave of an AIDS victim near Lwamagwa trading centre in Rakai district.

There are conspicuous signs this same scene has been played out numerous times before in the neighbourhood surrounding the late man's home. Every property on the path to nearby Lwamagwa trading centre is dotted with at least one but usually two graves. Crosses, made of wood or cement if the surviving family was lucky enough to scrape together the cash, poke out from bulges in the earth just like the fresh mound up the hill or from perfectly cemented-in rectangles. Some of the homes are empty because all of their former inhabitants were dead. Others had been abandoned, the children of the deceased being cared for elsewhere by guardians or relatives. But some of the children of these AIDS victims have chosen to remain in their communities to run their own households.

Each gravesite, abandoned home, child-headed household, each orphaned child denied an education and forced into an early marriage, cheap labour or the sex trade to survive, each mother and father who die of AIDS in squalid, miserable conditions with only their children to care for them, each of these is further testimony not only of the ravaging impact of HIV/AIDS on families, communities and entire regions in Africa but also the failure of current strategies, policies and projects to improve the lot of those most in need. But what is the way forward? That is the question that will be explored in this final section.

In search of a made-in-Africa solution

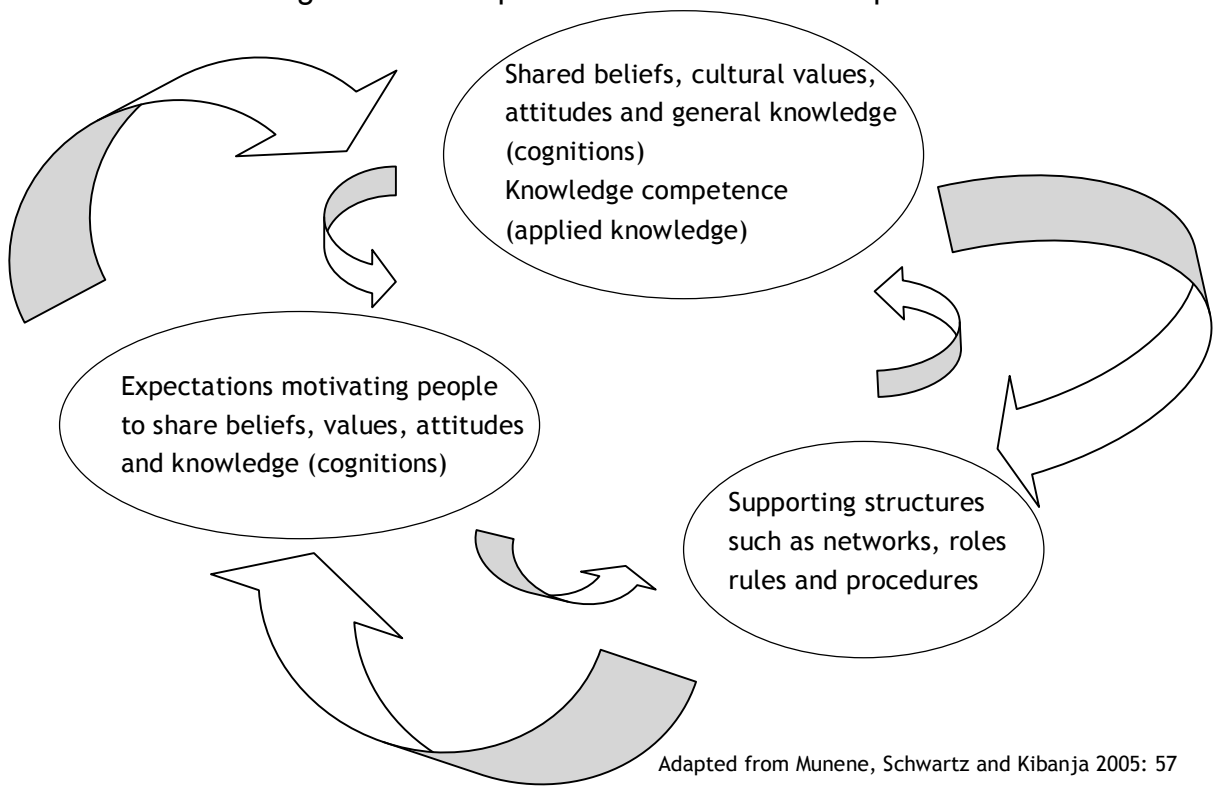
Thus far, there have been significant gaps between development theory and practice in Africa precisely because much of the theory has been born in a different context. Historically, it has been the international community and the ideological perspective of the donor community rather than Africans who have dominated the African development agenda. Efforts to define development have not adequately explored the questions: Who is defining the theory and why? Who has the power to define development? Who has the power to create and/or define development processes and its goals? Consequently, until recently, the development agenda has ignored or perceived as irrelevant the every day life experiences and consciousness of ordinary men, women and children whom development and humanitarian assistance seeks to help. The individuals who give rise to the statistics that macro-analyses uncover are still poorly understood and rarely considered.

Recently however, there has been growing recognition on the part of analysts and researchers (Sachs 2005: Commission for Africa 2005; Munene, Schwartz and Kibanja 2005) that "one size fits all", generic, blueprint policies that are not tailored to specific circumstances and situations are not working in Africa. Advocating the practice of a sort of "clinical economics … a thorough differential diagnosis, followed by an appropriate treatment regimen", Sachs insists, "a combination of investments well attuned to local needs and conditions can enable African economies to break out of the poverty trap" (2005: 83, 208).

Munene, Schwartz and Kibanja (2005) go one further. By emphasizing what the poor do or do not do rather than outcomes and end-result conditions, their perspective of poverty is informed by a people-centered, social capital model of development that represents a radical and perhaps urgently needed departure from previous perspectives. Since social capital is defined as "the capacity of individuals to draw on others in case of need and the capacity of communities to offer help [the social capital model of development] focuses on the actions that communities, individuals and households undertake that may or may not perpetuate poverty" (Munene, Schwartz and Kibanja 2005: 6). In order to develop successful poverty alleviation models, Munene, Schwartz and Kibanja (2005: 16-42) argue it is necessary to clarify not only which actions help poor people in Africa escape poverty, but more importantly "poverty carriers", which are futile or even harmful acts that produce or perpetuate poverty — acts that must change if individuals are to escape poverty, such as selling one's land, one's food crops or one's labour for a non-competitive fee, pulling one's children's out of school to sell their labour, marrying multiple wives. If these acts are identified, academics and practitioners can more easily design policies and studies to target these acts directly and deal with them systematically.

Munene, Schwartz and Kibanja insist, "the poor have much to contribute to formulating policy on poverty… [and the] failure to draw on the ideas of poor people when formulating poverty alleviation policies has probably contributed greatly to the continued poverty in Africa" (2005: 23). Moreover, their analysis of poverty alleviation projects in Uganda reveals that strategies originating from the poor themselves are most appropriate because "poor people were able to put their minimal education and contacts to work acquiring relevant knowledge and skills that fit their own capabilities. They provided simple but workable ideas that demonstrated a high degree of motivation to achieve" (2005: 22-23).

Figure 2: Conceptual definition of social capital



Adapted from Munene, Schwartz and Kibanja 2005: 57

More empirical data is needed to conclusively prove the effectiveness of the social capital model of development, but that will require a better balance between macro- and micro-policies. Thus far there have been plenty of experiments on macro-policies centered on growth in Uganda but too few trials of micro-policies. To plan such projects, "policy-makers must first acquire an intimate understanding of the daily activities of those whom they are targeting and of their surrounding environment … the focus of such policies must move from outcomes (e.g. income levels) down to the goal-directed actions of the poor (e.g. how they generate income)" (Munene, Schwartz and Kibanja 2005:

23). Projects that do not adequately appreciate the actions that cause poverty are unlikely to bring sustainable improvements and actually may even run the risk of making the poor dependent, argue Munene, Schwartz and Kibanja (2005: 23).

Culture plays a central role in development

The link between culture and development is also becoming widely recognized. History demonstrates that African culture has been "tremendously adaptive, absorbing a wide range of outside influences, and impositions, as well finding ways to survive often difficult natural environmental and social conditions. Such influences are not all positive … but culture is an agent of economic and social change" (Commission for Africa 2005: 31-32).

As the second largest continent in the world, containing more than 50 countries, Africa is hugely diverse, but research (Munene, Schwartz and Kibanja 2005) suggests black African nations share some significant, identifiable cultural values and practices. The research also shows that Uganda, in particular, has a prototypical African cultural profile. These cultural values profoundly influence everyday life in Africa as well as the interactions between African nations and Western European donor nations. Munene, Schwartz and Kibanja (2005: 43-81) hypothesis that one of the reasons development policies have failed to relieve increasing poverty in Africa is they have been crafted and imposed mostly by Western European donor countries whose cultural values contrast sharply with those of African nations.

Table 4: The dimensions of the seven cultural value orientations

Embeddedness versus autonomy focuses on the nature and sources of the identity of societal members in relation to their groups. In high embeddedness cultures, people find personal meaning and significance in their identification with their groups and in the pursuit of group goals. In high autonomy cultures, in contrast, people find personal meaning and significance in cultivating their own unique intellectual and emotional capacities.

Hierarchy versus egalitarianism focuses on how to govern productive relations within society, thereby assuring responsible social behaviour that gets necessary tasks done. In high egalitarian cultures, people are socialized to internalize a commitment to the welfare of others out of a recognition of human interdependence and moral equality. In high hierarchy cultures, people's positions in hierarchical social structures are used to motivate them to meet role obligations.

Mastery versus harmony focuses on the place of humankind in the natural and social world. In high mastery cultures, the emphasis is on active control and change of the social and natural environment in order to progress. In high harmony cultures, the emphasis is on maintaining peace and harmony, co-existing with people and nature as they are rather than trying to change them.

Source: Munene, Schwartz and Kibanja 2005: 10

Using data from over 60,000 respondents in 65 countries on all inhabited continents, Munene, Schwartz and Kibanja measured seven cultural value orientations on which national cultures are discriminated and they conclude that it is justifiable to view the African nations and Western European nations as broad cultural regions, at least in terms of their profiles on the seven cultural value orientations that were studied. The study (2005: 48-49) reveals a sharp mismatch of cultural value priorities between African and Western European donor nations. Culturally, samples from the

African countries endorsed hierarchy, embeddedness and mastery values but gave little legitimacy to autonomy, egalitarianism and harmony values. In contrast, the samples from the European nations endorsed the opposite set of values — autonomy, egalitarianism and harmony values, and they gave little legitimacy to embeddedness, hierarchy and mastery. Table 4 describes the main differences between the cultural value orientations. The mismatch in cultural values "raises the problem of intercultural communication and creates a cultural interface plagued by opportunities for conflict. It suggests that substantial misunderstanding, miscommunication, and mismatching of goals and interpretations of events will occur in contacts between people socialized in the West European donor nations and in the African client nations" (2005: 70). Thus, "working together can be expected to produce psychological and personal tension that may lead to organizational instability [and] it is unlikely that genuine dialogue is possible without deliberate efforts on both sides to face their cultural differences" (2005: 50).

The Commission for Africa (2005: 30) also has acknowledged differences in cultural values as they relate to perceptions about development. Many in Western countries see development through the prism of the modernization paradigm; that is, impoverished regions of the world like Africa simply need to 'catch up' with the developed world. In Africa, by contrast, "you will be more likely to be told something to do with well-being, happiness and membership of a community. In the West development is about choice for individuals; in Africa it is more about increasing human dignity within a community. Unless those who shape Africa's development make this integral to the way they formulate their policies they will fail."

Research by Munene, Schwartz and Kibanja (2005: 70) confirms that fundamental conceptions about the nature of individuals and their relations to the group, which prevail in African and Western European donor nations, differ substantially. "Africans are likely to emphasize the role of the individual as a group member who derives meaning from shared ideas, ideals, practices, and fate (Embeddedness). In contrast, West Europeans are more likely to view the individual as someone who derives meaning from his or her distinctive experiences, ideas, ideals, personality and aspirations (Autonomy)." Munene, Schwartz and Kibanja (2005: 80-81) conclude that when the "values [Africans] are prepared to accept and defend are in line with [development] project objectives and practices, potential project beneficiaries or implementers are likely to be motivated to participate and promote the intended project objectives. If on the other hand these objectives and practices are grounded in values they are predisposed to ignore or reject, they are unlikely to cooperate in the implementation of the project on a sustainable basis."

Although it is a necessary but not sufficient condition for development, "those who ignore culture are doomed to failure … the overall lesson is that outside prescriptions only succeed when they work with the grain of the African ways

of doing things. They fail where they ignore, or do not understand, the cultural suppositions of the people they seek to address. The international community must make greater efforts to understand the values, norms, and allegiances of the cultures of Africa and in their policy-making display a greater flexibility, open-mindedness and humility" (Commission for Africa 2005: 32-33).

Three negative cultural influences

Munene, Schwartz and Kibanja (2005: 53-55) identify three generically negative culturally patterned beliefs, values and practices that are problematic for development in Africa and therefore must be clarified at the onset of any development program. These include gender roles, the economy of affection, and a attribution of causation.

A considerable amount of previous research associates continued poverty in Uganda and other areas of Africa with culturally-determined gender roles. Gender role expectations, in combination with cultural commitments to hierarchy and to patriarchy, marginalize women by perpetuating and justifying gender inequality, the gender distribution of labour and treating women as less worthy than men.

The economy of affection, which is the practice of mutual help when it is practiced in the context of a market economy, worked well for indigenous organizations but appears "to wreak havoc with the operation of capitalist-oriented bureaucracies in Africa. The economy of affection imposes particular social obligations on public office holders, perpetuates localism, and undermines the emergence of a cosmopolitan outlook. It is manifest in tribalism, nepotism, and sectarianism … [and it is] an economy which encourages acquisition for the limited purpose of servicing the needs of perceived dependants, including friends. Because all available wealth is devoted to meeting the immediate needs of dependants, accumulation of the savings and property needed to develop productivity over time does not occur. The resilience of the traditional institutions of the economy of affection in the face of attempts at socio-economic change in Africa prevents the emergence and penetration of productive capitalist structures" (2005: 54).

Africans tend to favour a supernatural understanding of causality over empirical causation, which marginalizes sustained scientific and intellectual quest and weakens the scientific basis for understanding and mastering the environment in Africa. As a result of this cultural orientation, Africans are likely to draw upon rules and dictates of superiors to resolve difficult negotiations, rather than to examine all sides of an issue without preconceptions in order to find innovative and creative solutions. A major consequence of this cultural orientation is the continued existence of a non-science-based technology and a lack of the sort of science-based technology that has taken root elsewhere in the world, which relies on systematic testing

and evaluation of tools and products, their constant refinement and improvement, and their widespread distribution to the public.

In order to address the negative impact gender roles, the economy of affection and anti-scientific causality have on development it will be necessary to identify, make explicit and examine jointly with the community the values that perpetuate and justify these cultural practices in search of alternative cultural value preferences.

Social networks are critical

In Africa, the process of escaping poverty isn't so much one of action as interaction since social networks are especially critical to development. Largely "invisible to many outsiders, what can appear to donors as a form of anarchy is in fact structured; it is just that these are structures which Westerners are not trained to perceive. Africans survive — and some prosper — in the face of low incomes and few jobs in the formal economy. They do so using a complex network of social relations … These networks may be informal but they reveal how African people will get involved in activities where they can see purpose and direction" (Commission for Africa 2005: 30)

Bridging and bonding mechanisms, which are grounded in shared cultural values, are particularly important in generating social capital and creating the environment necessary for development projects to be set up well and for individuals to take advantage of these projects, according to Munene, Schwartz and Kibanja (2005: 58-61). Bridging refers to the activity of linking networks, communities and individuals to others. Through bridging activities, groups and communities obtain skills, information, and other resources they need to overcome their own shortages of resources — shortages that prevent them from developing and progressing in the direction they desire. Bonding refers to the commitments individuals or groups make to one another — commitments that lead to voluntarily helping acquaintances or the community. Bonding is grounded in trust and reciprocity. Both of these mechanisms are absolutely crucial for organizations such as PARDI, which are focused on promoting community development. "That is, in order to develop, a community needs members who are willing, committed and able to invest in one another and in the larger group (bonding). And, because no community or individual lives in isolation, it needs members who act to link it to other communities and to the wider society in order to tap new resources required to progress (bridging)" (2005: 59).

KEY LESSONS LEARNED

•Although it has not been scientifically quantified, it's clear that Uganda's national AIDS program has not been effective in reaching vulnerable people in the counties where PARDI operates. Moreover, it appears that a substantial number of vulnerable people in this area who are infected with and affected by

HIV/AIDS are not receiving support from non-governmental organizations either. A 2004 study in Rakai district found that 48.9 per cent of CHHs receive no support from NGOs (Rakai Community Based AIDS Project 2004).

•Like most other nations in sub-Saharan Africa, state welfare provisions in Uganda are limited, which means the well-being of most of the vulnerable people PARDI assists depend almost entirely on the capacity of the community to support them. But since traditional family and community coping mechanisms and organizations like PARDI are too overstretched to assist everyone in need, an alarming number of children and other vulnerable people are slipping through existing social safety nets. Unless government agencies, NGOs and/or donors begin providing assistance, it's likely these children and vulnerable people will continue to be denied the basic human right to live a decent life.

•Analysts (Jackson 2002, Center for Global Development 2003, UNAIDS 2001) agree community-driven and owned strategies that capitalize on local expertise are essential to an effective response to the HIV/AIDS epidemic in sub-Saharan Africa because they hold the greatest potential for sustainability. Jackson argues, "rather than external services attempting to take over community problems, the existing community care and coping initiatives need support to continue and to develop to meet changing needs" (2002: 277). According to UNAIDS (2001: 109), "an important lesson learnt … in a wide variety of settings is that national HIV/AIDS responses cannot reach the necessary scale, maintain quality, or provide the necessary flexibility by acting solely through the centrally operated programs. A decentralized, participatory approach — ie. with involvement of all sectors — is the only way to get wider coverage and enable programs to reach all those who are hard to reach, especially at the grassroots level. For example, most national AIDS programs have not been effective in reaching people — especially youth and women — in rural areas. However when they are willing to work in partnership with NGOs who have special expertise with these populations, a great deal can be accomplished." The Center for Global Development (2003: 8) concludes, "community networks, existing facilities, and multisectoral initiatives can all serve as catalysts to expand programs' impact." Yet CBOs continue to be under-funded, underappreciated and generally the contribution they are making in sub-Saharan Africa is still poorly understood. Moreover, very little effort has been made to evaluate impact of the activities of CBOs like PARDI. In fact, it was not until 2004 that any meaningful effort was made to catalogue community involvement in care and treatment in sub-Saharan Africa.

•Experts (Jackson 2002 and Center for Global Development 2003) also confirm that a multi-sectoral and holistic response — that integrates prevention, care, treatment and support — is the most effect approach to managing HIV/AIDS. PARDI employs just such a strategy with the exception of treatment, which the CBO simply does not have the resources or skills to provide. PARDI does provide

some basic home care that the government health system cannot afford or is not organized to offer. The CBO also refers patients for more complicated treatment to the hospital system, thereby extending the continuum of care available to patients. Still, a significant number of PARDI's target beneficiaries cannot afford to access such health care services and consequently a disturbing number of PWAs receive virtually no treatment or medication as they have no alternative but to die miserable deaths at home.

•The most significant challenge facing PARDI is an inability to muster sufficient financial resources to carry out its programs, especially in response to increasing numbers of orphans. The organization also contends with overwhelming workloads and unpredictable weather conditions such as drought and heavy rainfalls that adversely affect agricultural activities leading to poor yields and destroys people's property respectively.

•Like most other CBOs in sub-Saharan Africa, PARDI has almost no financing available and survives on meager contributions from PARDI members and well-wishers from abroad. (Despite applying for hundreds of grants over the years, thus far the only funding the CBO received from government was three million USh or approximately $2,500 CA in 2004 through Rakai district's Community HIV/AIDS Initiatives). PARDI's attempts to recruit volunteers and to mobilize community support for its programs are hampered by the fact that poverty is endemic in Rakai district. Over 70 per cent of households in the community it serves are estimated to survive below Uganda's subsistence level of 5,000 USh (approximately $4.15 CA) per week. Still, the community has demonstrated a willingness and commitment to invest in one another. For instance, during an Aug. 6, 2005 community meeting, local leaders pledged to PARDI three goats, 55,500 bricks and labour, one kilogram of improved seeds, one bag of cement, two trips of sand, four acres of land for construction and agriculture, transportation for pledged materials and counseling, two chickens, 25 dozen exercise books, two dozen pencils and pens, second hand clothing, six iron sheets and 200,000 USh.

•There is a gender dimension to the issues PARDI is attempting to address. Guardians tend to be women and daughters are more likely than sons to care for sick parents. Girls tend to be lured into early marriages as a means of survival and are therefore less likely to head child-headed households as they grow older. Boys form the majority of children living in CHHs.

•PARDI has an intimate understanding of the every day activities of those targeted for support as well as their surrounding environment because they live in the same communities as the organization's target beneficiaries. According to the social capital model of development (Munene, Schwartz and Kibanja 2005), such knowledge is essential to developing effective projects. Moreover, the organization actively engages its targeted beneficiaries, in other words the poor themselves, in the formulation of poverty alleviation and humanitarian

assistance policies and projects. It has been argued (2005: 103-125) that this "bottom up", "people-centred" approach is more likely than any other strategy to achieve the ultimate objective of participation in development which is empowerment. Empowerment occurs when decision-making and control of development projects is in the hands of the individuals for whom they are intended to support.

•An evaluation of PARDI's activities using the social capital model of development advocated by Munene, Schwartz and Kibanja (2005) and presented in Table 4, reveals that PARDI is endeavouring to address many of the most serious acts that give rise to or perpetuate poverty. Column 1 lists the common poverty carriers of PARDI's target beneficiaries. Whenever OVC are pressed into service at home, flee to urban centres in search of work, are forced into early marriages or engage in behaviours that increase their risk of contracting HIV, they hinder their opportunities to reach their full physical and intellectual potential and they condemn themselves to poverty in the long run and in general. Actions such as the economic exploitation of children who sell their labour for meager pay and the disposing of or loss of one's land also promote poverty because they cause the beneficiaries to use up or lose the means of production that are essential to alleviate individual and household poverty. Column 2 summarizes the mutually-reinforcing conditions from which PARDI's target beneficiaries suffer. These poverty indicators have been explained in detail in previous sections. Column 3 outlines strategies PARDI has employed to address these issues, including activities to help target beneficiaries earn external sources of income, improve their food security, protect their land, eliminate the social isolation associated with HIV/AIDS and protect against the mistreatment, abuse and discrimination of vulnerable people affected by the virus. Strategies also include measures to encourage OVC to remain in rural areas, where they have a better chance of survival, and efforts to sensitize the community about HIV/AIDS to encourage prevention through behaviour change. Column 4 suggests recommendations for PARDI.

•PARDI appears to have had a great deal of success reducing the stigma, isolation and discrimination attached to HIV/AIDS. During field visits, PWA and vulnerable people infected with and affected by the virus spoke openly about the disease and if stigma exists, it was not discernible.

•Bonding mechanisms, crucial to the generation of social capital, appear to be especially strong in the environment in which PARDI operates but bridging activities are weak as these activities have not resulted in the attainment of the essential skills, information, and other resources needed to overcome shortages of resources that prevent the CBO from assisting its beneficiaries.

Table 4: Poverty Carriers and poverty Indicators of PARDI's target beneficiaries

(1) POVERTY CARRIER	(2) POVERTY INDICATORS	(3) STRATEGIES	(4) RECOMMENDATIONS
•Children pressed into service at home to care for others •Children selling their labour in exchange for food or meager pay •Girls forced into early marriage as a means of survival •Flight of children to urban areas in search of work •Parents suffering from AIDS drawing down savings and selling assets to prolong their lives •Increased workload for women •Increasing number of elderly caring for children they cannot support •Property grabbing •Sexual and economic exploitation of OVC •Engaging in behaviour that increases the risk of contracting HIV	•Death of parents •Lack of food security •Lack of cash to buy clothing, bedding, medicine and other basic necessities •Reduced access to health care and education •Inadequate shelter •Inability to cope with disease •Lack of social support •Social exclusion •Lack of relatives •Loss of traditional values •Emotional and mental stress •Psycho-social distress	•Vocational training and income generating activities for OVC so they can find external sources of income •Training in modern agricultural practices to improve food security •Sensitization about HIV/AIDS and the problems of OVC through children's drama and choir performances and one-on-one counseling to reduce stigma, isolation and discrimination and to encourage prevention through behaviour change •Equal access to programs for girls and boys •Recruiting guardians for orphaned children and supporting CHHs to discourage flight to urban centres •Establishing community networks to identify vulnerable people in need •Supporting development of community protection mechanisms for OVC and	•Continue formulating policies with active participation of the target beneficiaries, but make more effort to increase decision-making authority, control and responsibility of projects, possibly by establishing and/or strengthening involvement of OVC committees •Keep beneficiaries informed about PARDI developments and improve procedural transparency by regularly disclosing expenditures, assets and strategic decisions •As resources allow, scale up activities to improve agricultural productivity •Address gender-based inequality by providing girls and women with awareness and related skills development, recruiting more women for leadership roles, and sensitizing men and boys to change their harmful behaviour towards girls and women within the

		monitoring caregivers to ensure OVC are not being mistreated •Mobilizing support from key community stakeholders to assist vulnerable people through the provision of land for orphanage centres, food production, and a school; donations of money, livestock, food, clothing, scholastic materials, etc.; and, the construction of homes and water tanks •Assisting with will making to protect land and other assets for orphaned children	household and community •Implement sensitization programs for community members to change harmful behaviour towards OVC within the household and community •Recruit volunteers to focus on advocacy work for OVC, girls and women and to lobby for change •Expand existing drama and choir groups to encourage participation by even more children and explore the possibility of offering more sports and recreational activities at orphanage centres •If and when resources allow, scale up support to children who are living with a parent with AIDS •Increase community awareness and accountability about the property rights of women and children and mobilize support to enforce and uphold those rights

•PARDI staff are extremely cynical about and disillusioned with the process with which the national government supports HIV/AIDS programs. The organization alleges there are serious malpractices in the way available funding and resources are allocated. They charge the process is rife with nepotism, diversion of funds and embezzlement. These allegations echo charges revealed during an inquiry into the Ugandan government's mismanagement of millions of dollars from the Global Funds to Fight AIDS, Tuberculosis and Malaria. During the inquiry, it was alleged the government forged receipts, diverted funds for political campaigns, and engaged in serious accounting malpractice (BBC World Service, March 27, 2006). The Global Fund suspended all grants to Uganda except for life-preserving activities in August 2005 after an independent audit by PricewaterhouseCoopers discovered incidents of inadequate monitoring and accounting of expenditures for one of Uganda's grants to combat HIV. The suspension was lifted in November 2005 after Uganda and the Global Fund agreed to establish structures to oversee the implementation of grants, including: a self-assessment to ensure effective oversight of the Global Fund grants; continued involvement of the caretaker management firm Ernst & Young over a period of six to nine months to evaluate the quality and efficacy of all sub-recipients of grants; and, a restructuring process of the grants to streamline implementation, clarify responsibilities, and simplify grant oversight (PlusNews 2005).

• UNAIDS (2001: 109) has found that in many developing countries, HIV/AIDS projects are held back by a number of administrative challenges, which are not necessarily peculiar to HIV/AIDS, but common to all aspects of public administration and governance. These challenges, which exist in Uganda, include: lack of institutional capacity, including lack of trained managers and insufficient administrative infrastructure to manage given projects; slow, out-of-date bureaucratic procedures that choke initiative and reduce effectiveness; lack of procedural transparency, allowing inefficiency and corruption to 'eat' scarce resources; lack of follow-up, either because short-term political priorities 'hijack' carefully planned programs or because monitoring and evaluation are not built into planning cycles.

•PARDI is well-placed to identify and assist the most vulnerable, neglected people most in need of support if and when support from the national government, other NGOs and/or international donors is scaled up. In fact, district authorities already rely on the CBO to identify needy and vulnerable people in the community.

KEY RECOMMENATIONS

•Existing projects to help mitigate the impact of the epidemic on vulnerable people in the counties where PARDI operates are insufficient to address pressing human security challenges and relieve the suffering of all of those in need. In particular, AIDS-affected households, including those headed by HIV-

positive parents and by guardians, urgently require the basic necessities of survival. Whether in the form of income-generation projects, vocational training or training in improved agricultural practices, food, clothing, home repairs, or school fees, such material support is essential to ensuring AIDS-affected people are able to exercise their basic human right to live a decent life. Such projects must address the actions that give rise to poverty in order to be effective and sustainable over time. As column 3 in Table 4 on pages 63-64 indicates, many of PARDI's strategies to mitigate the impact of HIV/AIDS do just that, but unless the CBO's community driven and owned activities are sufficiently resourced, the projects will be ineffective and an increasing number of vulnerable people will fall through the social safety net. National government authorities and international donors must start recognizing, supporting and strengthening CBOs like PARDI or the organizations will have to continue relying on meager donations of cash and resources from ad hoc, unpredictable sources.

•Despite operating under extreme fiscal constraints, some additional activities, recommended in column 4 in Table 4 on pages 63-64, likely would not be too costly for PARDI to implement. These include stepping up efforts to increase decision-making authority, control and responsibility of projects to the beneficiaries, especially children, possibly by establishing and/or strengthening involvement of OVC committees as well as improving PARDI's procedural transparency, including regularly disclosure of financial accounts, expenditures, assets as well as key strategic decisions to beneficiaries. The CBO should consider building on the remarkable success of its HIV/AIDS sensitization programs by incorporating a gender component that would sensitize men and boys in particular about the need to change their harmful behaviour towards girls and women. Educating girls and women about their rights and related skills development as well as recruiting more women for leadership roles would also help address gender inequality. PARDI should explore the possibility both of expanding its hugely successful drama and choir groups to encourage even more participation by OVC and spearheading regular, ongoing sports and recreation activities at orphanage centres as an inexpensive way to further integrate OVC with their peers and maintain their psycho-social well-being. In an effort to change social norms as well as national policy and legal frameworks, PARDI should consider recruiting volunteers to focus specifically on advocacy work for OVC, girls and women and to lobby for change. To combat property grabbing, PARDI should embark on a community awareness campaign about the property rights of women and children. In addition to training more men as well as women to write effective wills, the campaign should encourage communities and leaders to uphold and enforce the property rights of women and children. To be effective, the campaign must engage probation officers, who are vested with the authority by the district government to resolve conflicts over land and other family disputes, as well as the police, the Local Council I chair and vice chair, who is responsible for child welfare issues that arise in the village. Since subsistence farming is critical for

the survival of almost all OVCs and their families, PARDI should scale up activities aimed at improving agricultural productivity through measures such as labour saving techniques, high yield seeds, high breed animals, animal husbandry skills, and modern farming practices. Such measures increase household incomes of OVCs so they can avoid hiring out their labour for cash and food. Support to OVC might also include helping OVC make informed business and investment decisions so they can protect themselves against exploitation by unscrupulous people.

•Architects of educational programs as well as vocational, agricultural and skills training for OVCs must be mindful of the fact that most of their income generating activities are labour intensive and time consuming. Programs must be tailored in such a way as not to compromise the means of survival of OVCs. Public education systems also must take this fact into consideration and make appropriate concessions for these children.

•Prolonging the lives of PWA and their ability to care for themselves and their families directly benefits children, who face fewer human security challenges as long as their parents are alive. It follows, therefore, that the sons and daughters of PWA who receive free ART will have brighter futures. This is a compelling reason for scaling up free access to ART for adults and children in sub-Saharan nations. In addition, too few children of PWA currently are being tested for the HIV in the counties where PARDI operates. This gap must be addressed and HIV-positive children must be included in ART programs.

•PARDI and district authorities currently collaborate on the provision of some health outreach services, but more needs to be done to further integrate NGO care with existing HIV/AIDS and other health services. “Ideally, the formal health system, NGOs and other potentially well-resourced and professional institutions should be fully linked with home and community care, with as a high degree of community ownership and active participation as possible” (Jackson 2002: 239).

•Coordination and cooperation between NGOs, district and national government agencies and the community needs to be enhanced to strengthen NGOs and CBOs that are already supporting vulnerable people infected with and affected by HIV/AIDS in Rakai district and to enable other NGOs and CBOs to extend their services to people in need.

•PARDI should take advantage of any opportunity to improve its organizational capacity, especially in the areas of strategic planning, financial management, and administrative practices.

•Given that state welfare provisions are unlikely to improve in Uganda in the short-term, it is imperative the national government refocus its role and develop strategic partnerships within a clear framework. As long as

communities and CBOs like PARDI remain on the forefront of identifying needy children and other vulnerable people, they will need access to external support to provide effective care and support through their existing and new structures. Whenever possible, direct government support "may supplement provisions in a few extreme cases, but the roles of policy development, monitoring and coordinating support jointly and democratically with others are central" (Jackson 2002: 281). Furthermore, strengthening and supporting community-based responses to HIV/AIDS requires NGOs, governments and other development agencies to take some risks. Support must be channeled directly to CBOs like PARDI and the organizations must be trusted to control and disburse funds. "NGOs, government departments and other agencies, where appropriate, need to provide back-up monitoring, liaison between donors and recipients, support accounting and management processes with the community, and ensure effective evaluation" (Jackson 2002: 282).

•To that end, UNAIDS (2001: 110-111) highlights a model institutionalized by the Programme for AIDS Initiatives in Ecuador, a national-level NGO that provides grants and technical support to help other organizations carry out local-level HIV/AIDS activities. In managing its relationships with NGO and CBO partners, the program's staff emphasize the following recommendations that would be useful for any governments, NGOs and international donors that fund HIV/AIDS projects:

1. Staff need to know and understand the candidate NGO or CBO well before signing grant agreements with them. Sometimes the candidate organization's motivation can be simply that of obtaining funds, rather than mounting a serious response to HIV/AIDS. Although it provides no guarantee, an in-depth analysis of each candidate partner can help screen out such organizations.
2. Many NGOs and CBOs need support in preparing their initial project proposals to help them be more realistic based on the local situation and the NGO/CBO's resources and experience. A community assessment is very important in this process.
3. The NGO/CBO support organization (in this case, the Programme for AIDS Initiatives) should avoid training the target population directly. It should instead carry out training of trainers, to help the NGO or CBO gain technical credibility in the community, rather than always waiting for the 'experts' to come and visit. This also raises the level of sustainability of their work and the NGO, as they can work independently of the support organization.
4. It is important to document the different tools and methods developed, as much of the experience could probably be beneficial to other organizations doing similar work.
5. Field visits are crucial to a good monitoring system. Reports and office visits only can give a partial view of reality and must process of reflection and analysis within the NGO and CBO. At certain times they need to stop and evaluate their impact and processes so they can attempt to improve them.
6. Finally, "Always recognize the existing knowledge and experience of the NGO or CBO and the target population. No work starts from zero."

•Direct government support is imperative to address the issues of abuse, neglect, and/or sexual and economic exploitation of OVC, which requires "appropriate legislation, and commitment to human rights and its effective implementation through government, NGOs, community mobilization and other efforts" (Jackson 2002: 280).

•Analysts (UNAIDS 2001, Jackson 2002) stress the importance of a decentralized and participatory approach to the AIDS crisis in sub-Saharan Africa. In fact, the Ugandan government has been gradually and incrementally decentralizing services, control and even some resources to the district level for several years now. But it isn't clear whether the Ugandan government possesses the necessary commitment and political will to genuinely empower families and communities, which is bound to lead to a heightened awareness and political consciousness and a significant reallocation of resources. The prospect of grassroots society insisting on greater accountability and transparency from their elected leaders and more control over public finances may threaten powerful vested interests in Uganda. According to Hyden (1994: 315), "development management is increasingly being shared by a broadening range of public, private and voluntary organizations. This growing institutional pluralism poses a special challenge to African governments, which have grown used to a monopoly of power. Most of them have been reluctant to give NGOs and other society-based institutions the autonomy they demand in order to do their work effectively."

Some final thoughts about my field practice…

My professional field practice as PARDI's media relations officer/resource mobilizer provided me with an invaluable opportunity to merge my theoretical knowledge about the field of peacebuilding and human security with hands-on practical experience in one of the worst AIDS-ravaged regions of the world.

My activities included:
•Facilitating the publication of a newspaper article about PARDI in the Victoria News and writing a column featuring a case study of AIDS-affected children PARDI supports for CBC.ca;
•Writing articles based on my field experiences and photographing images to pitch to various media outlets;
•Creating a database of PARDI's organizational structure, case studies and background information on Rakai and Sembabule districts.
•Capturing photographs and motion pictures of PARDI volunteers and beneficiaries and creating a database of these images;
•Producing a PowerPoint presentation about PARDI and its work;
•Home visits to assess the most urgent needs of OVC, PWA and other vulnerable people, many of whom live in remote areas and whose needs are hidden from government social service agencies and other NGOs;

•Provision of outreach services and material assistance to AIDS orphans and other vulnerable people in remote areas who receive no support from government social service agencies and other NGOs;
•Researching, identifying and making inquiries about possible funding sources, including using my personal networks to broaden awareness about the organization in an effort to raise funds;
•Drafting and submitting grant applications to US Embassy in Kampala and a humanitarian assistance organization based in Victoria, BC;
•Attendance and participation at PARDI community meetings;
•Responding to queries from potential donors;
•Making inquiries with other NGOs that are assisting AIDS orphans and other vulnerable people infected with an affected by HIV/AIDS.
•Raising a total of $2,557 CA, mostly from family and friends, for the organization. The money raised provided food to 37 CHHs and 268 vulnerable people during a period of heightened food insecurity and emergency medication and health care services for three orphans who were suffering from typhoid fever and hookworms. Just over half of the funds were used to construct a large water tank at an orphanage centre and two small water tanks that will each supply safe drinking water to up to five families. In addition to the sum raised by family and friends, I personally donated approximately $700 CA to PARDI for food for OVC and their families, fuel for field visits, art supplies for three orphanage centres, a bicycle for the coordinator of one orphanage centre, and approximately 100 blankets for OVC who participated in the research project.
•Collaborating with PARDI field programmer Hagaba Richard on decisions about how these funds should be administered.
•I'd hoped to design a research project that would test the hypothesis that supporting the so-called AIDS "orphan generation" requires "community driven and owned" strategies. (See application for IDRC research grant in Appendix C: Field Activities). But due to limitations in resources and my inability to secure a research grant, this field research project was modified and scaled down. This study is explained fully on pages 22 to 38 in the section, "IN THEIR WORDS, BY THEIR HANDS: The most pressing human security challenges of children affected by HIV/AIDS as revealed through their drawings, letters, skits and songs". I intend to explore the possibility of selling some of the artwork created in the study as a fundraiser for the organization. If possible, I also hope to collaborate with an art therapist to do some further analysis of the psycho-social needs of the children who participated in the study.
•Although I have officially completed my professional field practice, at least as far as fulfilling my requirements for HSP 690 go, I've resolved to continue trying to raise PARDI's profile and to mobilize resources and support for the organization in the future.

Just like PARDI, the most significant challenge I encountered is a lack of resources — both monetary and technological. As the completion of my placement requires access to good, reliable Internet services, I've been

dividing my time between Lyantonde and Kampala, where I reside. While in Lyantonde, my accommodation and food was provided for by PARDI, but beyond that I was required to use all of my own equipment and to cover all of the costs associated with doing my job, which includes but was not limited to: transportation to and from Lyantonde; Internet access; printing, photocopying and scanning services; mobile telephone services; visa extension fees; and, accommodation in Kampala. As I had no income while I am completing my placement (other than small stipends I received for freelance columns I completed while in Uganda as well as a research project I worked on in addition to my placement), I had to do everything I could to stretch my personal monetary resources, to be as resourceful and self-reliant as I could.

The underwhelming response I received to the dozens of queries and inquiries I made in an effort to mobilize funds for PARDI and broaden awareness about the plight of the vulnerable people the organization supports was frustrating to say the least. In fact, I do not think I've ever worked so hard to accomplish so little. The potential funding sources I uncovered do not provide assistance to the geographical areas where PARDI operates and/or they target assistance for very specific purposes or beneficiary groups as opposed to organizations like PARDI, which support vulnerable people in need through a multi-sectoral, integrated and holistic approach. Admittedly, fundraising isn't exactly my forte, but I found it extremely difficult to gauge just how much funding is available from NGOs, the national government, donors and the international community for CBOs like PARDI. If these funds exist, they are not easy to find and access and competition for grants that are more well-known is stiff.

During my stay in Uganda, I was often asked for handouts and loans, which I found extremely awkward and only compounded my frustration and angst. As one *Newsweek* columnist poignantly observed: "…in the West poverty means a bad life. But poverty in the Third World means death. For the one billion people who live on less than $1 a day, one bad cold, one unlucky fall, one month of poor rainfall, and they or their children will die" (Zakaria, 2005: 15). These facts are not lost on me. It is not easy to say 'No' when the need is so great and the poverty so extreme. I expect being able to say 'no' with a clear conscience will continue to be a significant challenge for me.

The poor quality of the technological infrastructure that I have access to also impeded my progress. It was not unusual to spend 45 minutes trying to send one e-mail and power outages are a frequent occurrence. (For several weeks prior to my return to Canada and at the time of writing this report, Ugandans were experiencing 24-hour blackouts due to a shortfall in hydroelectric power). The equipment at Internet cafes is not always reliable. An important lesson for me, therefore, was learning how to manage my own expectations about what I can realistically accomplish and, out of necessity, to practice patience, which is a virtue I can honestly say I've never been generously endowed with.

Although the academic portion of Royal Roads University's (RRU) MHSP program provided me with an excellent theoretical foundation upon which to venture out into the field, I found it overwhelming, at times, to process and make sense of everything I experienced. It is one thing to read about the issues of human security and peacebuilding in news reports and books, but it's quite another to encounter them up close and personal. The scale and intensity of the poverty suffered by so many of the people PARDI supports is almost incomprehensible. If I didn't see it with my own eyes, I wouldn't believe it. There is so much to do and so little money to do it that it's difficult not to suffer a sort of paralysis of the psyche as a result of the terrible psychological weight of helplessness in the face of such destitution and deprivation. After several months in the field, I still do not know how it is possible to assess and triage the most critical, urgent needs when so many require so much and the resources to assist them are so limited. How does one adequately address the root causes of the problem so that what we're doing is not akin to slapping a Bandaid on arterial bleeding? That is a question I still do not really feel capable of answering and this has challenged me to learn to cope with ambiguity and uncertainty without becoming completely numb and withdrawn. Although field experiences and the personal reactions they evoke and provoke vary from person to person, it would have been helpful to have spent some time during our residencies exploring these issues and brainstorming constructive coping mechanisms.

Without a doubt, the most valuable thing I gained during the field placement is what the influential sociological theorist Max Weber referred to as "verstehen", an empathetic understanding of the experiences of those I was working with, attempting to assist and researching. The field placement helped me both to make sense of and put a human face to the cold, stark, macro statistical analysis of the AIDS epidemic in sub-Saharan Africa. Suffice it to say, I wholeheartedly agree with Weber that empathetic experience is "an important source of knowledge that offers an intersubjective understanding of other people's lives … [as well as] a deep appreciation of the full context within which people live their lives" (Sullivan 2001: 325). But to gain "verstehen", "researchers need to view and experience the situation from the perspective of the people themselves. They need to talk to the people at length and to immerse themselves in the lives of those people so they can experience the highs, lows, joys, sorrows, triumphs, and tragedies as seen from the perspective of the people being studied" (Sullivan 2001: 49). I'm convinced that field placements such as the one I completed and other participatory action research can help bridge the gap between theory and practice by making the local, contextualized realities of people paramount in theoretical debate.

As a result of me experiences in the field, I have learned a great deal about the power of kindness and generosity, as well as the indomitable strength and resiliency of the human spirit in the face of unimaginable adversity. Although

many of those I've met are extremely impoverished, their lives possess a richness that money simply cannot buy. I have come to admire how masterfully Ugandans honour and value their relationships, to marvel at their patience and utter refusal to sweat the small, petty stuff that drives so many Canadians crazy and to envy how accomplished they are at spontaneously reveling in the joys of life. I'm tremendously appreciative of the hospitality and helpfulness of PARDI volunteers and staff and I am awestruck by their determination, commitment and resolve, which never seem to waver despite all of the obstacles in their way. I've been touched by the willingness of the organization and their beneficiaries to accept me as one of their own community and I'm very proud to say I have even adopted into the Monkey clan and christened the Luganda name, "Nakabugo", which means aunt. The support of my family and friends in Canada and their willingness to donate money to assist PARDI has moved me. As I've already mentioned to many of them, it buoys my spirit, renews my hope and restores my faith because I'm convinced it's a demonstration to me and those they've helped, who are among the most marginalized people on the globe, that our common humanity binds us together. In Africa, the word for this is "ubuntu", "I am what I am because of who we all are." The needless and senseless suffering of the most innocent victims of humankind's worst contemporary tragedy has seared my consciousness and left a scar on my conscience. But the grace and dignity these children display in their courageous, inexorable struggle for survival is at once humbling and inspiring. I will never forget them. How could I? Our lives are inextricably bound together. As long as their struggle continues so does mine.

APPENDIX A:

FACTS & FIGURES UGANDA AND RAKAI

DATA	YEAR	ESTIMATE	SOURCE
Total population (thousands)	2004	26,699	UN population division database
Population aged 15-49 (thousands)	2004	11,234	UN population division database
Annual population growth rate (%)	1992-2002	3	UN population division database
% of urban population	2003	12.2	UN population division database
Average annual growth rate of urban population	2000-2005	3.9	UN population division database
Crude birth rate (births per 1,000 pop.)	2004	50.8	UN population division database
Crude death rate (deaths per 1,000 pop.)	2004	15.8	UN population division database
Maternal mortality rate (per 100,000 live births)	2000	880	WHO (WHR2004)/UNICEF
Female population aged 15-24 (thousands)	2004	2,686	UN population division database
Total fertility rate	2002	7.1	World Health Report 2004, WHO
Infant mortality rate (per 1,000 live births)	2000	89	World Health Report 2004, WHO
Under 5 mortality rate (per 1,000 live births)	2000	147	World Health Report 2004, WHO
Gross national income, ppp, per capita (Int.$)	2002	1320	UN population division database
Gross domestic product, per capita % growth	2001-2002	3.6	World Bank
Per capita total expenditure on health (Int.$)	2001	57	World Health Report 2004, WHO
General government expenditure on health as % of total health expenditure	2001	57.5	World Health Report 2004, WHO
Adult male illiteracy rate	2000	22.5	UNESCO
Adult female illiteracy rate	2000	43.2	UNESCO
Total adult illiteracy rate	2000	33	UNESCO
% births attended by skilled health professionals	2000	37.8	WHO
Contraceptive prevalence rates (%)	1995	14.8	UNICEF/UNPOP
Life expectancy at birth (years)	2002	49.3	World Health Report 2004, WHO

Adapted from UNAIDS/WHO epidemiological fact sheets on HIV/AIDS on Sexually Transmitted Infections, 2004 Update (2004: 3, 9)

UGANDA HIV/AIDS FACT SHEET

Estimated number of adults and children living with HIV infection, whether or not they have developed symptoms of AIDS, alive at the end of 2003:

Adults and children	530,000	
Adults (15-49)	450,000	Adult rate (%) 4.1
Women (15-49)	270,000	
Children (0-15)	84,000	

Estimated number of deaths due to AIDS during 2003:

Deaths in 2003	78,000	

Estimated number of orphans - children who have lost their mother or father or both parents to AIDS and who were alive and under age 17 at the end of 2003:

Current living orphans	940,000	

Estimated number of adults 15-49 with advanced HIV infection receiving ARV therapy as of June 2004:

Adults on treatment	20,000	

Estimated number of adults 15-49 in need of treatment in 2003:

Adults on treatment	110,000	

Knowledge of HIV prevention methods - percentage of young people 15-24 who both correctly identify two ways of preventing the sexual transmission of HIV and who reject three misconceptions about HIV transmission in 2000:

Male	40	
Female	29	

Reported condom use at last higher risk sex of young people 15-24 ie. sex with a non-regular partner in 2000:

Male	62	
Females	44	

Adapted from UNAIDS/WHO epidemiological fact sheets on HIV/AIDS on Sexually Transmitted Infections, 2004 Update (2004: 2)

RAKAI DISTRICT PROFILE

Established in 1974, Rakai district is located in southern Uganda and borders Lake Victoria to the east, Tanzania to the south, Mbarara and Masaka districts to the west and north respectively. At the time of the last national census in 2002, the population of Rakai district was 471,806. About 96 per cent of the population was rural based and dependent on agriculture, livestock and fishing. There were 239,544 females and 232,262 males.

The district is linked by tarmac road from Kampala to Rakai district headquarters, while the main trunk road from Kampala to southwestern Uganda cuts through Lyantonde in the northwest of the district. Although a number of roads have been upgraded, intra-district communication is still relatively poor.

Rakai is predominately a mixture of sedentary Baganda agriculturalist and pastoral Banyankole; the latter being concentrated in the northern part of the district in Kabula and Kooki counties. Ninety per cent of the district's population is Christian.

Vegetation in the district varies. In the south, near Lake Victoria, there is forest and swamp; in the north there is savannah. Only 180 kilometres of the district are still forested. Rainfall patterns vary considerably in the district. Adequate rainfall coupled with moderate temperatures during rainy season ensures a favourable agricultural environment around the lake.

The northwest, which is predominantly savannah grasslands, is more suitable for livestock production. There are two rainfall peaks, March to May and October and November. Soil fertility is low in many areas and hillside erosion is an increasing problem particularly in Kooki county.

Cultivation of bananas, sweet potatoes, cassava, maize and beans is the principal means of livelihood for 70 per cent of Rakai's population, although a proportion of these crops are marketed within and outside the district. Coffee is Rakai's chief cash crop. Agricultural techniques and technology are essentially basic and the main source of agricultural labour is the family. Despite the reliance on agriculture, food insecurity still poses a serious threat. For example, in 1992 and 1998 drought resulted in serious food shortages throughout the district.

Livestock and fishing are also important economic activities. Livestock production is also primarily organized within family units. Tilapia and Nile perch are fished on the three lakes of Victoria, Kijjanebalola and Kacheera. Fish processing is carried out using traditional methods of preservation. Sale of fish to traders in Kampala is reportedly on the increase due to improvements to access roads.

Trade is the third largest activity in Rakai. The most lucrative type of trade, accounting for over 70 per cent of the district trade volume, is retail trade in manufactured goods for domestic use. Trade in agricultural products is also significant, especially cross border trade with Tanzania. Rakai has very few industries and the few small-scale coffee and maize processing operations that do exist are concentrated in urban centres.

Poverty is endemic in the district. Over 70 per cent of the households are estimated to survive below Uganda's subsistence level of 5,000 Uganda Shillings or $3 US per week. Many of the problems associated with poverty have been exacerbated by the HIV/AIDS epidemic. Infection rates have been higher in the district's trading centres than its rural areas. Girls in the 13 to 19 year-old age group have significantly higher infection rates than males in the same age group in trading centres. There are no observable gender differences in the 20 to 29 year-old age group, but infection rates in rural areas are reportedly higher among women in the 30 to 39 year-old age group.

Source: Rakai Community-based AIDS Project, 2004: 7-9

RAKAI STATISTICAL SUMMARY	
Area	4989 sq km
Distance from national capital	190 km
Counties	4
Sub-counties	23
Parishes	120
Villages	850
Population	471,806
Annual growth rate	3.04%
Urban population	3.8%
Rural population/subsistence farmers	77.4%
Female-headed households	31.7%
Orphans who have lost one parent	17.9%
Estimated number of orphans	65,000
Estimated number of CHHs	900
Children under 5	20%
Children between 12-19	17.3%
Male to female ration	49%/51%
Infant mortality rate	119/1000 (1997)
Under five mortality rate	137/1000
Maternal mortality	60/1000
Total fertility rate per woman	7.7%
Illiteracy rates	57.9% (female 30.2%.male 29.7%)
Doctor to population level	1:31,958
Population living under the national subsistence line	70%
Safe water coverage	33% (1994)
Safe latrine coverage	68%
Life expectancy	Females 50/Males 45.3 years

Source: Rakai Community-based AIDS Project, 2004

APPENDIX B:

PARDI

END OF THE YEAR STATEMENT - DECEMBER 20, 2005
For Participatory Action for Rural Development Initiative (PARDI)

By Hagaba Richard
Program officer PARDI

1.0 Introduction

Dear partners, associates, stakeholders, well-wishers, fellow colleagues and comrades, I do take this unique opportunity to make an End of Year Statement as we come to a close of this year, 2005. One of the great pleasures of writing the End of the Year Statement is the opportunity it affords to congratulate, register appreciation, take stock and recall the good things done by colleagues, partners and friends. I do wish to congratulate you for the work well done for the last twelve months and the problems you have been able to surmount. In the same vein, I do wish you a very happy, prosperous and blessed New Year, 2006. May you live to enjoy the fruits of your hard labour.

I note with delight, satisfaction and measured pride, that despite the many challenges, ranging from lack of funding to unpredictable weather changes, PARDI has remained firm on humanitarian axis, steadfast in a professional direction and afloat social environmental turbulence and storm. For the last twelve months, the staff of PARDI have offered their energies, knowledge, wisdom and service in line with the project goal and its vision of empowerment of the community to promote meaningful sustainable development through active community participation, a "people centered approach" to development, and to provide a conducive atmosphere for the growth and development of children. We therefore have a cause to celebrate the end of the year and some achievements registered collectively

I feel so honoured and privileged to have had an opportunity of working with a group of dedicated, determined and vibrant staff to offer a visible service to humanity. Since the beginning of this year, I have witnessed with evident pleasure, PARDI staff reaching out and serving the project beneficiaries; humbly, unselfishly, determinedly, radically, lovingly, unconditionally and sacrificially. Gratitude, respect and measured pride. These words sum up how I feel about PARDI staff.

2.0 Acknowledgement

Without the timely support and encouragement of partners and well-wishers, PARDI would not have been able to register meaningful tangible achievements. Although the extent of my debts cannot be fully acknowledged here, it is nevertheless a joy to record my gratitude and appreciation to many people and organizations / agencies who have helped; some without realizing just how helpful they were:-

- All volunteers both foreign and local with PARDI staff in lyantonde and Kampala respectively, you have measured to the challenges of this year, 2005.
- The beneficiaries of PARDI; the orphans, the widows, the widowers, the elderly, the sick and the marginalised. You have given us an opportunity to serve you, to learn from you and to measure our intellectual and professional capacity against the needs you present.
- The district leadership and opinion leaders. Thank you for owning the project.
- Volunteer counsellors; through you, we have been able to reach out to many intended beneficiaries, register visible achievements and scale up the project impact. We do owe you a debt of gratitude.

- Our donors; Individuals of the local community, Church leaders, Alanna Jorde and her mother Tanya and Ted Jorde, The Black Press Victoria Ltd. And its President Jim Tighe, The Black Press Victoria staff Association, Tavis, Bertha and Garth, Betty Brightwell, and Heather Scott all from Canada, PARDI Staff and others. Without your support, especially during the last quarter of 2005, good plans and ideas would have only remained on paper!! PARDI is deeply indebted to you for your support and expressed interest to support the initiative.

- It is also a pleasure to acknowledge my debt to all NGOs working in Rakai District, for the very close working relationship and allowing yourselves to grow with us.

The responsibilities given to us in PARDI have always been enormous, the expectations of our target beneficiaries have been very high this year, and yet the means at our disposal to measure to the expectations together with the set objectives have been grossly inadequate. We started the year with a lot of hope but no resources. In May 2005, some foreign partners promised some financial support but it did not yield as expected therefore, PARDI staff and programs became tantalized, leaving many good plans and ideas on paper. From January up to December, the project depended on pre-financing arrangements from Staff contributions and a few financial contributions from both Canada and Japan individual partners and also on the local community church, due to inadequate funds, it negatively affected PARDI activities. Meanwhile, partners from Canada and Japan have expressed interest to lend a hand. Hence we expect to remain afloat next year in 2006.

Experience has taught me over the years to go beyond politics of grievance and complaint, and engage in politics of production. This means; to think positively, to escape the circle of concern, jump into the circle of influence, learn from others, be creative and be confident. Success lies in your own power to produce. It is not having wealth; it's having the power to produce wealth. This philosophy is very much believed by PARDI staff to whom I do owe a debt of gratitude.

On behalf of PARDI, I would like to express my absolute delight at the positive results achieved by our staff through partnership, cooperation and commitment. I do register my sincere appreciation to all our partners and stakeholders for the over-whelming support over the year. Together, we have worked to serve humanity and register a visible impact in Rakai District-Uganda. Through me, PARDI beneficiaries do record their gratitude and joy to all who have contributed to the betterment of their lives in one way or another.

3.0 Personnel

This year the project has collaborated with 340 volunteer counsellors, 5 AIDS Educators and 10 un-paid staff. PARDI has had an opportunity of hosting foreign volunteers from North America, Asia and East and Central Africa.

A number of our project staff had opportunities of visiting other countries, attended workshops and conferences: Early this year 5 members of staff visited a sister project in Karagwe Region in Northern Tanzania; 3 staff attended the International Conference on HIV / AIDS in Nairobi, Kenya; 2 staff attended a conference of Churches United in Africa against HIV / AIDS (CUAHA) in Dar-es-Salaam-Tanzania. A total of 20 staff participated in a two-week training workshop on Participatory Rural Appraisal, while 2 had training and refresher training in SPSS computer package and Micro-soft project respectively.

PARDI methodology of work based on simplicity, speed, feasibility, adaptability, flexibility and professionalism has been a major impetus for the project success. Last year, 2004, PARDI Management applied the seven - Cs formula (competence, courage courtesy, confidence,

creativity, character and control) with great success. This year, the project moved another mile and employed the principles of DIVERSITY leadership to the benefit of all and to the detriment of none.
Discipline
Industry
Vision
Enabling and Empowerment
Respectability
Service
Information
Team building
Yielding

PARDI staff have been highly disciplined, industrious, visionary and enabling to the admiration of both friends and foes. The project staff are highly regarded and respected in Rakai District, as they unwaveringly offer service humbly, sacrificially, loving and determinedly. The project has collected and disseminated a lot of information, maintained a team spirit throughout and inevitably yielded some good results.

4.0 Developments and achievements

- ∞ Maintained a committed and well-motivated workforce of 21 un-paid staff and 51 volunteers.
- ∞ Provided counselling service to over 4000 people
- ∞ Conducted a courses for 89 AIDS Educators
- ∞ Annual project development fora exercise was successfully carried out in 13 sub counties and 52 parishes attracting more than 17,500 people. This is a deliberate and conscious effort to sensitize the public on the dynamics of PARDI and offer them opportunity to evaluate PARDI activities.
- ∞ A well-trained group of 79 volunteer counsellors was passed out after completing one and half years' counselling course.
- ∞ As a follow - up to earlier research on the effectiveness of traditional herbs and healers, a herbal medicine programme including the establishment of herbal gardens, was introduced. This has attracted both local and international attention and a group of medical practitioners from Britain is planning to come next year and do a research in this area together with the project.
- ∞ The project is planning a research to establish the effectiveness of a combination of counselling, vocational therapy and nutrition / local herbs in the mitigation of AIDS symptoms and consequences.
- ∞ Working with the district health department PARDI scaled up the health -outreach programme.
- ∞ Extended food relief to 147 vulnerable families.
- ∞ Gave technical support to 555 Community Based Groups.
- ∞ Received and worked with 1 volunteer from Canada an accomplished and versatile journalist
- ∞ Hosted 2 journalist from Denmark and Japan Respectively.
- ∞ Hosted 17 people from Tanzania.

5.0 Challenges

- ∞ Failure to get funding crippled activities and left many project plans and ideas on paper.
- ∞ Funds from expected sources did not yield in September; this called for changes in strategies and added extra burden on staff and the project programs.
- ∞ Unpredictable weather changes
- ∞ Lack of fundraising strategies
- ∞ Planting pillars of sustainability amidst socio-economic challenges.

6.0 Lessons learnt and impact

- A community based and managed project should always involve communities and individuals as full and active partners rather than as passive "targets" or beneficiaries". This means that such a project will continue to function even without or when external assistance is no longer provided. These approach, yields immediate results and build a firm basis which allows the community to become active in identifying their own problems and taking action to address that and that is why PARDI has continued to exist.
- An empowering strategy is one, which gives the "partner" the confidence, skills and access to information to transform them from passive recipients into agents of change.
- Listening involves emotional strength, patience, openness and the desire to understand.
- For the last two years, PARDI has worked tirelessly to mitigate the socio-economic consequences of HIV / AIDS. Three major factors or ingredients have always been emphasized with greater success; counselling as a psycho-social support tool for mental stability; vocational therapy for calculated exercises to keep the "sick" active and engage in gainful economic activities to the advantage of the entire physiological set up of a person affected by the disease; and nutrition- eating locally available balanced diet.
- Many of PARDI clients have responded well to the above combination (counselling, vocational therapy and nutrition / local herbs).
- The project (PARDI) has a highly motivated staff and this is attributed to the participatory managerial style and a strong team spirit built over the years.
- The project dynamics are appreciated in the community because of the parish development fora and PARDI's presence in the field. Consequently, people's attitudes are positively changing towards hard work and sustained fight against diseases, ignorance and poverty.

7.0 Way forward and conclusion

This is the second and new phase of PARDI in Rakai District; 2006 - 2010; and probably, during this phase, the focus is to strengthen our address on the HIV and AIDS epidemic and ensuring food security. Therefore HIV/AIDS and food security remain major crosscutting issues among our activities.

Before I completed writing this statement, I received good news that partners from Canada and Japan have expressed interest to lend a hand. Hence we pray that this happens as expressed and this is indeed a timely and welcome gesture.

PARDI's relationship with Rakai District leadership and continued involvement of all stakeholders in project activities will remain unwavered. In case funds/resources allow, PARDI shall remain steadfast in making timely advances to enrich and modify existing strategic approaches to management, sharpening policy focal points, ensuring greater consistency between policies and instruments, enhancing capacities for timely change, advancing significantly in addressing the foundations of long term sustainable development and adopting greater pragmatism in creating new structures which will stand the test of time.

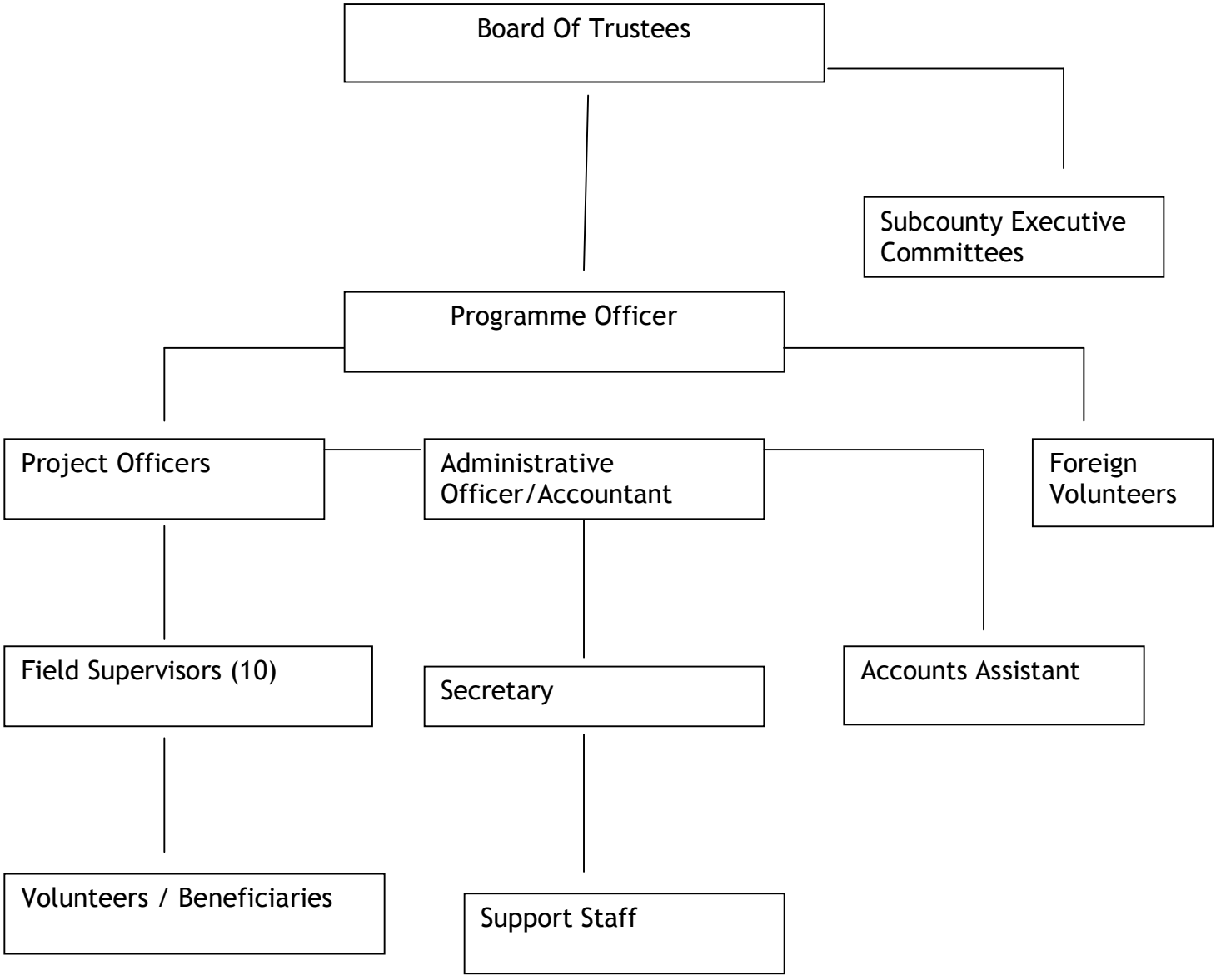
I have had a rare privilege of working closely with many different people from different background. I have witnessed PARDI staff investing a lot of energies and working beyond the call of duty in supporting poor communities in a sustainable way. In PARDI, we have had moments of deep concern (when there are no funds), potential crisis (when funding promises do not yield), moments of gratitude and achievements, moments of success in building a common front and perspective as highlighted in this statement. In such situations, the management of PARDI, has always been flexible, visionary, people centered and with ability to talk listening.

As a Program Officer, I have learnt a lot from PARDI staff; they are generally open minded and creative, able to forecast immediate dangers and seek solutions early enough. They have always used available little resources intelligently and sparingly to generate maximum results.

We have had a wonderful time together. PARDI is very proactive in highlighting social problems and campaigning for social change. We shall continue to be a powerful advocate of change in favour of the poor and dispossessed. PARDI staff will always be reliant on the good will, cooperation and support of all stakeholders.

Management Structure

A board of trustees, together with the programme officer, are responsible for making PARDI's key management decisions. A programme officer, who supervises a staff of three, manages the secretariat, which is the executive arm of the Initiative. At the grassroots, PARDI works through subcounty executive committees that link the organization with the community.



Goal

Improved quality of life of the rural poor affected by HIV/AIDS through active participation and sustainable rural "people-centered" development aimed at bringing about meaningful fundamental change.

Mission

To respond to challenges and consequences of human suffering, which alienates people from enjoying real life improvement and to promote human dignity through reducing suffering arising from diseases and poverty