Joint Learning Initiative on
Children and HIV/AIDS (JLICA)

Learning Group 3:
Expanding Access to Services and Protecting Human Rights

Integrated Health Care Delivery Systems for Families and Children Impacted by HIV/AIDS:

Four Program Case Studies from Kenya and Rwanda

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October 15, 2008

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SUMMARY

This document describes four family and community-centered approaches to caring for and treating HIV-affected children and households, three in Rwanda and one in Kenya. To date, millions of children and families affected by HIV/AIDS in sub-Saharan Africa have received few direct financial and material supports from the global public health community or governments. This absence is in spite of the extensive evidence documenting the detrimental consequences on children and households when one or more adult caregivers are sick with HIV. The four projects described all share a common commitment to delivery of care in the community rather than limiting provision of care to health facilities. These projects are: the Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH) in Western Kenya, CARE International's 5x5 Model for Early Childhood Education (ECD) and its Case Manager Pilot Program, both in Rwanda, and Partners in Health- Inshuti Mu Buzima Rwanda program (PIH/IMB). All of the projects share a commitment to providing comprehensive services to all family members—and especially children—in addition to sick patients. A broad and integrated range of services is aimed at alleviating some of the underlying conditions that aggravate vulnerability of families—especially women and children—affected by HIV. All rely significantly on paid and unpaid community health workers to provide services to combat malnutrition, poverty, and child vulnerability/mortality. In three of the four projects, community health workers are remunerated for their efforts. The report provides contextual historic background about the global community's growing recognition of the value of rooting, investing and building health and social service delivery systems at the community level as a way of reaching, treating and supporting HIV-affected families more effectively. Evidence presented in this report show that in Africa and other resource-poor settings family and community-centered care networks are often the key intersecting point for continuum of care services provided by hospitals and health facilities, support groups, and external referral services. Research also shows that prolonging the lives of HIV-infected parents/guardians through drug therapies, nutritional supports to the entire family and early childhood education aimed at children between the ages of 0-8 can render a far healthier environment for children than do programs that isolate benefits solely to individuals or orphans and vulnerable children.

After careful review and comparison of available program data several key indicators and themes began to emerge that might explain the tremendous success of the programs featured.

- An overall program philosophy rooted in social justice and the right for all patients to have access to a broad range of health care services, regardless of their ability to pay;
- An adherence to a broadened definition of health care that extends beyond traditional medical treatment to also include the linked provision of nutritious foods and access to psychosocial support, education, economic security, legal protections, clean water and basic shelter;
- A program architecture that revolves around the vital role of the Community Health Worker, who is highly trained, compensated and is sometimes HIV-positive her/himself;
- A sustainable, integrated food and nutrition component that is considered an essential patient right and is viewed as equally important as access to life-saving medicines.
- A community-based comprehensive health care delivery system that links medical and social support services directly to patients and families in need, thereby alleviating a significant burden of daily care away from overburdened health facilities in the formal sector;
- A strong commitment to hiring from within the community, a strategy that not only enhances drug adherence and program-patient relations, but also benefits families and communities by creating jobs, helping to reduce local poverty and serving as an HIV prevention tool; and

- Large infusions of operating costs provided by external donors.

Acronyms

AMPATH	Academic Model for Prevention and Treatment of HIV/AIDS
ART	Antiretroviral Treatment or Therapy
ARV	Antiretroviral
ASANTE	America/sub-Saharan Africa Network for Training and Education in Medicine
CHEW	Community Health Extension Workers
CHW	Community Health Worker
CM	Case Manager
CORP	Community Owned Resource Personnel
DFID	United Kingdom Department for International Development
ECD	Early Childhood Development
FBO	Faith-based Organizations
FCG	Family Care Giver
FOSA	Formation Sanitaire
FPI	Family Preservation Initiative
GF	Global Fund for HIV/AIDS, Tuberculosis and Malaria
HAART	Highly Active Antiretroviral Therapy
HHI	HAART and Harvest Initiative
IMB	Inshuti Mu Buzima
IFI	International Financial Institutions
INGO	International Non-Governmental Organization
IUSM	Indian University School of Medicine
MAP	Multi-Country HIV/AIDS Programs
NERCHA	National Emergency Response Council on HIV/AIDS (Swaziland)
NGO	Non-Governmental Organization
OVC	
RAAAP	Rapid Country Assessment, Analysis and Action Planning Process for Orphans and Vulnerable Children in sub-Saharan Africa
PEPFAR	US President's Emergency Plan For AIDS Relief
PIH	Partners in Health
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
POSER	Program on Social and Economic Rights
SSA	Sub-Saharan Africa
TB	Tuberculosis
TBA	Traditional Birth Attendants
VCG	Volunteer Care Giver
VTC	Voluntary Testing and Counseling
WFP	World Food Program
WHO	World Health Organization

—This paper was prepared for the Joint Learning Initiative on Children and HIV/AIDS (JLICA). The JLICA is an independent, interdisciplinary network of policy-makers, practitioners, community leaders, activists, researchers, and people living with HIV/AIDS, working to improve the well-being of HIV-affected children, their families and their communities. All reasonable precautions have been taken by JLICA to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall JLICA be liable for damages arising from its use. The author alone is responsible for the views expressed in this publication—.

Introduction

This report investigates the efficacy of four family and community-centered approaches to caring for and treating children and households infected and affected by HIV/AIDS in Africa. It aims to show that prolonging the lives of HIV-infected parents/guardians through drug therapies, coupled with additional socio-economic-nutritional supports to the entire family and early childhood education aimed at children between the ages of 0 and 8, can render a far healthier environment for children than do programs that isolate benefits solely to individuals or orphans and vulnerable children. The vast majority of people living with HIV/AIDS in Africa today are cared for in their homes by members of their own kin network, without the benefit of appropriate clinical care or the support of outside organizations.[1] The extremely challenging social, economic and agricultural conditions in sub-Saharan Africa (SSA) today demands that an integrated system of HIV/AIDS care and treatment concurrently address the issues of poverty, hunger, gender discrimination and stigma that continue to impede successful treatment and care and contribute to the spread of the disease.[2] This report provides contextual historic background about the global community's growing recognition of the value of rooting, investing and building health and social service delivery systems at the community level as a way of reaching, treating and supporting HIV-affected families more effectively. For the purposes of this paper, two academic medical programs—both of which boldly break with traditional notions of health care delivery—and one international non-governmental organization were studied: the Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH) in Western Kenya, CARE International's 5x5 Model for Early Childhood Education (ECD) and its Case Manager (CM) Pilot Program, both in Rwanda, and Partners in Health- Inshuti Mu Buzima Rwanda program (PIH/IMB).

National and Global Response to Providing Care and Support to Children and Families Affected by HIV/AIDS

National Responses

Since the early days of the pandemic in Africa the greatest burden of caring for people

[1] Department of Health, National Guidelines on Home-Based Care and Community-Based Care, South Africa, 2001.
[2] Einterz, R., Kimaiyo, S., Mengeck, Hl, Khwa-Otsyula, B., Esamai, F., Quigley, F., Mamlin, J., Responding to the HIV Epidemic: The Power of an Academic Model, Academic Medicine, Vol. 82, No. 8, August 2007.

living with HIV/AIDS (PLWHA) and the swelling population of children in need has fallen on families and communities. Many of these caregivers—a vast majority of who are female's living in poverty themselves—have not until recently if at all received any form of economic, food and other social support assistance from governments, donors and the international community at large.[3] There is substantial evidence indicating that the financial and physical burden of caring for PLWHA and children in need falls on already-impoverished households. In Kenya, for example, households pay 45-per cent of HIV/AIDS-related expenditures directly as out-of-pocket expenses, whereas the government pays for 30 per cent and donors pay for the remaining 25 per cent.[4] In Botswana, 47 per cent of orphan caregivers reported financial difficulty and 18 per cent said they were unable to meet basic needs.[5] Research shows that many of the rural poor in developing countries pay 85 per cent of the total cost of the health services they receive.[6] An estimated 90 per cent of HIV-positive people do not receive basic HIV/AIDS care from health facilities. Since state-administered support is often non-existent throughout much of Africa, the main form of social insurance for households facing crisis consists of supportive relatives, who are most often grandmothers, widows, aunts and sisters. Another survey of HIV/AIDS-affected households in several provinces of South Africa found that many of the affected families did not have access to home-based care programs or any kind of support from government but rather had to depend solely on family and community members to provide care for them. [7]

Research from South Africa demonstrates that most prospective caregivers would require financial and other types of assistance to care for additional children in their households.[8] A study in Mwanza, Tanzania, showed that family caregivers spent 3–7 hours every day in care-related activities and that nursing needy and dying patients placed a considerable socio-economic burden on them. This same study showed that due to strict cultural interpretations of the gender division of labor most men were unwilling to care for the sick except in circumstances where women were unavailable. [9] In a caregiver study from Botswana only three of the 35 caregivers interviewed were males.[10] Although the burden of care fell primarily on HIV/AIDS- affected families and communities, women in the

[3] Zoll, Miriam, *Securing Orphan Access to Education by Compensating HIV/AIDS Workers for Their Unpaid Labor*, Presented at Oxford University's 8th Annual UKFIET International Conference on Education and Development: Learning and Livelihood, October 2005
[4] *Kenya HIV/AIDS National Health Accounts Sub-analysis*, 2004.
[5] Heymann, J., et al, Extended Family Caring for Children Orphaned by AIDS; Balancing Essential Work and Caregiving in High HIV Prevalence Nations, AIDS Care, 19 (3), 337-345, 2007.
[6] Sachs, J.D., Macroeconomics and Health: Investing in Health for Economic Development, Report of the Commission on Macroeconomics and Health, WHO, Geneva, 2001.
[7] Steinberg, M., Johnson, S., Schierhout, G., Ndegwa, D., Hitting Home. How Households Cope with the Impact of the HIV/AIDS Epidemic: A Survey of Households Affected by HIV/AIDS in South Africa. Menlo Park, California, Henry J. Kaiser Family Foundation. Publication No. 6059, 2002.
[8] Freeman, M., Nkomo, N., Guardianship of OVC: A Survey of Current and Prospective South African Caregivers, AIDS Care, 18 (3), 302-310, 2006.
[9] Nnko, S., Chiduo, B., Wilson, F., Msuya, W. & Mwaluko, G., Tanzania: AIDS Care: Learning from Experience, *Review of African Political Economy* 27 (86), pp. 547–557, 2000.
[10] Lindsey, E., Hirschfeld, M., Tlou, S. & Ncube, E., Home- based Care in Botswana: Experiences of Older Women and Young Girls. Health Care for Women International 24(6), pp. 486–501, 2003.

study were disproportionately affected, constituting 68 per cent of the primary caregivers.

National governments' attempt to provide basic living assistance—food, health care, educational access, shelter, clothing and psychosocial services— to children in need and PLWHA were, and in many cases still remains, extremely limited. Inadequate monitoring and evaluation, shortages of trained staff, difficulty accessing or processing birth and death certificates, and a range of additional infrastructure challenges plague national efforts to respond.[11] In the early years of the pandemic it was not uncommon for governments to assign HIV/AIDS responsibilities to ministries that lacked the political clout and the budgetary power necessary for rolling out sustainable long-term responses. This same pattern holds true today among many ministries charged with improving care and support to children in need and their families. For example, in Malawi, the Ministries of Gender and Community Services, and in Nigeria, the Federal Ministry of Women Affairs and Youth Development, are the lead government agencies coordinating national responses to assist children in crisis. In both countries, women and children's rights are often not enforced, nor are legal reforms protecting women and children's rights necessarily a priority. It is ironic that those in charge of cultivating an effective response for children in need and HIV-affected families are the very ones who are viewed as invisible, second class citizens by traditional, and to some extent, civil laws. Given this context, it is not surprising that governments and donors have not always prioritized strategies to expand financial assistance, care, and support to HIV-affected families and communities, including caregivers.[12]

Lack of governmental response was and remains due in part to the structural adjustment policies of international lenders set forth in the 1980s and 1990s. Many of these policies mandated that governments privatize formal health and social service sectors that traditionally served the poorest and most vulnerable citizens.[13] Though state services often ran inefficiently in the sub-Saharan African (SSA) region, they did in fact provide some relief to the poor and generated jobs for primarily female health and social service workers.[14] In Ghana, for example, between 1984 and 1991, after privatization of the 42 largest state enterprises, 150,000 workers lost their jobs.[15] These cutbacks in public sector employment disproportionately affected women who traditionally held positions, such as clerical workers, cleaners, nurses or teachers. In Ghana, the least skilled women

[11] Executive Summary: OVC RAAAP Final Report, The Policy Project in Support of OVC RAAAP Initiative, USAID, UNICEF, UNAIDS, WFP, January 2005
[12] Zoll, Miriam, *Securing Orphan Access to Education by Compensating HIV/AIDS Workers for Their Unpaid Labor*, Presented at Oxford University's 8th Annual UKFIET International Conference on Education and Development: Learning and Livelihood, October 2005
[13] Sparr, P., 1994, "Mortgaging Women's Lives: Feminist Critiques of Structural Adjustment, Zed Books for the United Nations, pg. 214
[14] Bangura Y., 2001, "Public Sector Restructuring: The Institutional and Social Effects of Fiscal, Managerial and Capacity Building Reforms," United Nations Research Institute for Social Development, pg. 53, Geneva.
[15] Bangura Y., 2001, "Public Sector Restructuring: The Institutional and Social Effects of Fiscal, Managerial and Capacity Building Reforms," United Nations Research Institute for Social Development, pg. 53, Geneva.

working in the public sector lost job protection, security, and benefits as a consequence of policies aimed at increasing efficiency, while others lost employment altogether. [16]

The timing of the downsizing of these state services in Africa collided with rising HIV infection rates, mounting health care needs and the early deaths due to HIV/AIDS of professionals trained in health care delivery and management.[17] The death toll of so many professionals working within the government system in Botswana, for example, significantly hampered the state's efforts to respond to the pandemic, including bolstering child and family welfare assistance. As President Festus Mogae said in a 2003 speech in Washington, DC:

"It should be borne in mind that one impact of the pandemic has been to reduce our own capacity to deal with it, since many of our own people have died. We have recruited others. They too have died. And to the extent that we have suffered these losses, our management capacity to deal with HIV/AIDS has been diminished. And this is why we have done some things less quickly than had been intended or hoped." [18]

Quickly overburdened by the demands of the pandemic many economically weak governments, with encouragement from international policy makers and donors, began relying on the unpaid caring labor being delivered by family members in HIV-positive households and those absorbing orphans and other vulnerable children in need. Initial efforts to draw the burden of care away from a dismantled formal health care sector often demanded hospital-based outreach that required staff to travel directly to patients' homes to provide care. These programs proved to be time-consuming and expensive, especially in rural areas.[19] In the 1990s the World Health Organization in consultation with a broad group of experts developed a framework for *Comprehensive Care Across a Continuum*, one of the first official documents articulating the needs of families and communities coping with the taxing burden of care.[20] This framework placed the person living with HIV/AIDS at the center of a wide range of actors who were 'dynamically linked'. The entry point to the 'continuum' was voluntary counseling and testing for HIV, with home care as one element of the broader system of care provision. [21] This health-based continuum framework attempted to bridge isolated family and community care providers—mostly women and girls living in poverty—to a broader range of existing clinical resources provided by the state, international donors, INGOs and NGOs. Some

[16] Sparr, P., 1994, "Mortgaging Women's Lives: Feminist Critiques of Structural Adjustment, Zed Books for the United Nations, pg. 214
[17] DeJong, J., Making an Impact in HIV/AIDS: NGO Experiences of Scaling Up, London: ITGD Publishing, 2003.
[18] Mogae, Festus, November 2003, President of Botswana, speech to CSIS Task Force on HIV/AIDS and Members of the Bush Administration, Washington, DC.
[19] Chela, C.M., Assessing the Cost-Effectiveness of Home-Based Care in Zambia. Paper presented at the 2nd International Conference on Home and Community Care for Persons Living with HIV/AIDs, 24-27 May, 1995, Montreal, Canada; Hansen, K., Chapman, G., Chitsike, I., et al, The Costs of Hospital Care at Government Health Facilities in Zimbabwe with Special Emphasis on HIV/AIDS Patients, Blair Research Institute, Ministry of Health and Family Welfare, Harare, Zimbabwe, 1998.
[20] Osborne, C., van Praag, E., Jackson, H., Models of Care for Patients with HIV/AIDS, AIDS 11 (Suppl. B): S135-41, 1997
[21] The Health Workforce: Current Challenges, WHO/EIP/HRF/2004.2.Geneva: WHO

scholars have criticized this approach for not acknowledging the more complex needs of individuals and families' in their efforts to access psychosocial support services, ensure educational access for children, provide HIV/AIDS prevention tools including those appropriate for illiterates, or offer nutritional support, legal protections and shelter.[22] The case studies featured in this report streamline these broader needs by siphoning them through a human rights-based approach that stretches far beyond other health and social service care delivery models employed in resource poor settings.

Global Response Supporting Children in Need and Their Families

Infants and children orphaned and made vulnerable by HIV/AIDS are among the most at risk casualties of the global AIDS pandemic. An estimated 2.1 million children under the age of 15 are living with the HIV virus and an estimated 200,000 are currently receiving antiretroviral therapy (ART).[23] Approximately 15.2 million children under the age of 18 in the SSA region have been orphaned and made vulnerable as a result of AIDS.[24] The number of orphans and vulnerable children in SSA are expected to climb to more than 20 million by 2010.[25] Research and data compiled by UNICEF indicate that orphans are more likely than non-orphans to miss out on schooling, live in poor households that experience food insecurity, suffer from anxiety, depression and grief, and have a higher risk of exposure to HIV infection.[26]

A unified global effort to assist these children did not materialize until June 2001. Almost three decades after the pandemic first emerged on the public health radar screen, nearly 50 countries signed onto the United Nations General Assembly Special Session (UNGASS) Declaration of Commitment on HIV/AIDS, which included a core set of indicators applicable to orphans and other vulnerable children in need. Two years later, UNICEF convened a broad coalition of stakeholders through the Inter-Agency Task Team to reach consensus on a set of ten core indicators to measure national progress toward improving the welfare of children in need. At the First Global OVC Partners Forum held in October 2003 an agreement was reached for greater collaboration to rapidly scale up and improve the quality of response to orphans and other vulnerable children. The significance of the earmarks for the African countries within the US President's Emergency Plan For AIDS Relief (PEPFAR) was highlighted during this forum.[27] Subsequently, USAID, UNICEF, UNAIDS and the World Food Program (WFP) outlined a desire to conduct a massive rapid assessment exercise as a preliminary step to scale up the response to the growing crisis. By 2003 it had become clear that the head on collision of ineffective prevention and treatment, infringements on women and children's human rights, deepening poverty, and crippled public health infrastructures

[22] Ogden, J., Esim, S., Grown, C., Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus, Oxford University Press, 2006.
[23] UNAIDS/WHO/UNICEF, Toward Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector, Progress Report, 2008.
[24] UNAIDS and WHO, AIDS Epidemic Update, 2007
[25] UNAIDS/WHO, 2004 Report on the Global AIDS Epidemic
[26] UNICEF, Africa's Orphaned and Vulnerable Generation, New York, 2006.
[27] Executive Summary: OVC RAAAP Final Report, The Policy Project in Support of OVC RAAAP Initiative, USAID, UNICEF, UNAIDS, WFP, January 2005

now constituted a major natural disaster for children and families that needed to be evaluated and assessed in a more comprehensive manner.[28] From 2003-2005, USAID, the UN and Futures Group International conducted an unprecedented investigation of policies and programs benefiting children in need in 17 SSA countries that has since become a baseline for measuring progress in this arena. The multi-year initiative was known as The *Rapid Country Assessment, Analysis and Action Planning Process for Orphans and Vulnerable Children in sub-Saharan Africa* (OVC RAAAP). Initial countries studied were: Botswana, Central African Republic, Cote d'Ivoire, Ethiopia, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe.

A year later, in July 2004, UNICEF and UNAIDS joined with a broad range of multi-sectoral representatives to solidify *The Framework for the Protection, Care, and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS.*[29] Those engaged in this worldwide endeavor were donor and government agencies, faith-based (FBOs) and non-governmental organizations (NGOs), academic institutions, the private sector, and civil society representatives. The five tenets that comprise *The Framework,* first presented in UNICEF's *Children on the Brink* in 1997,[30] represent a common agenda that has since been adopted by numerous stakeholders, including JLICA and the programs featured in this report, to support, interpret and mobilize family and community-focused responses to the pandemic:

- #1 Framework Strategy: Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial, and other support.

- #2 Framework Strategy: Mobilize and support community-based responses to provide both immediate and long-term support to vulnerable households.

- #3 Framework Strategy: Ensure access for children in need to essential services, including education, healthcare, and birth registration.

- #4 Framework Strategy: Ensure that governments protect the most vulnerable children through improved policy and legislation, and by channeling resources to communities.

- #5 Framework Strategy: Raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV/AIDS. [31]

[28] Ibid
[29] www.unicef.org/aids/files/Framework_English.pdf
[30] Williams, John, *Strategic Action Developed for Children and Their Families*, 2003
[31] UNAIDS and UNICEF, 2004, "Children on the Brink 2004: Strategies to Support Children Isolated by HIV/AIDS, New York.

Defining, Costing and Understanding the Value of Family and Community-Centered Care

Often under a mandate from key donors such as the PEPFAR and the Global Fund for HIV/AIDS, Tuberculosis and Malaria (GF), many service providers are today striving to deliver 'integrated' and/or 'family-centered' care for PLWHA and children in need by reaching the entire family rather than targeting care specifically to orphans or vulnerable children. Despite the global rhetoric calling for such comprehensive models to be funded and implemented, considerable ambiguity still surrounds the meanings and applied interpretations of these terms and the delivery systems that most effectively embody them.

What Is Family and Community-Centered Care?

Based on research for this report, there appears to be no uniformly recognized definition of family and community-centered care approaches, or of community home-based care, though both concepts are referred to frequently and interchangeably in the context of HIV/AIDS care delivery systems. Some research differentiate family-centered care from a family-centered approach, which is explained as "*comprehensive, coordinated care that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs, either directly or indirectly through strategic partnerships and/or linkages and referrals with other service providers.*"[32] Additional research on the subject found that the family-centered care approach is based on a bio-psychosocial system approach where the primary focus of healthcare is the client in the context of their family, and the client, family, and clinician are partners in healthcare.[33] In the 2001 Gaborone Declaration the Southern Africa Development Community defined community home-based care as the "*care given to an individual in his/her own environment (home) by his/her family and supported by skilled welfare officers and communities to meet not only the physical needs, but also the spiritual, material, and psychosocial needs*" of the patient and his/her family members.[34] Following suit, the WHO defines community home-based care as "*any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities.*"[35]

In December 2001, the South African government published its National Guidelines on Home-Based Care/Community-Based Care to assist with the implementation of such health care delivery throughout the country.[36] Although the guidelines recommend the

[32] Dirks, R., et al, "Children Thrive in Families: Family Centered Models of Care and Support for OVC Affected by HIV/AIDS, JLICA LG1, January 2008.
[33] McDaniel, S., et al, "Family Oriented Primary Care: A Manual for Medical Providers, New York, NY: Springer Science & Business Media, Inc., 2005.
[34] 1st Southern Africa Development Community Conference on Community Home Based Care, Gaborone Declaration on Community Home Based Care, March 8, 2001.
[35] Gilks, C., Floyd, K., Haran, D., et al, Sexual Health and Health Care: Care and Support for People with HIV/aids in Resource Poor Settings, Health and Population Occasional Paper, London: Department for International Development, UK, 1998
[36] Department of Health, National Guideline on Home-Based Care and Community-Based Care, South Africa, 2001.

involvement of the formal healthcare sector and other stakeholders, the primary responsibility for care and support continues to fall to communities and immediate families of the sick and vulnerable. In its *Policy Framework for Community Home-Based Care in Resource-Limited Settings* the WHO in 2002 sought to develop guidelines and frameworks to assist national governments in developing more systematic multi-sectoral responses to families' growing care needs.[37] Though important for accelerating attention to family-centered care in general terms, this particular WHO framework was criticized for not explaining the specific difficulties unlinked, unpaid care workers experienced while attempting to access and piggyback with existing local resources. In addition, the document did not address how many caregivers' own families were being economically and psychosocially compromised as a result of donating their time and labor outside their own homes.[38]

Research from South Africa captured through interviews the poignant emotional, physical and economic stresses caregivers must contend with on a daily basis. Family caregivers (FCG) and volunteer caregivers (VCG) who had lost more than one patient were generally in a state of psychological distress at the time of the interviews. They stated that their frequent experience with the death of patients was extremely disturbing emotionally and haunted them continually: *'I have the fear that the emotional pain I feel might affect me sometime in the future, because the things I experience always come back to my mind; it is not easy to deal with these things'* (28-year-old, FCG/VCG). Others who experienced physical ailments as a result of caregiving linked it to the emotional pain that they carried. One 35-year-old woman who had given up her temporary domestic work to care for her mother explained, *'I always felt pains at the back of my head, and I don't know what it is, but I think it is due to the fact that I was thinking and worrying too much because I wondered a lot as to what my mother was suffering from'* (35-year-old FCG). [39]

Research conducted in 2003 by HelpAge International, a London-based INGO working on behalf of millions of elderly worldwide, indicates that in order for family and community-centered care to be truly holistic it must be simultaneously aligned with and integrated into poverty reduction, health, education and sustainable development strategies.[40] As stated by UNICEF in *The Framework for the Protection, Care and Support of OVC*, HIV/AIDS has a significant impact on the morbidity and mortality of adult members of households who are crucial to the survival and well being of children. Therefore, interventions that focus on children in need should also assess the needs of their surviving parents or other adult caregivers. Ideally, program interventions for children affected by HIV/AIDS should be designed to link the entire family—adults and

[37] Community Home-Based Care in Resource-Limited Settings: A Framework for Action, Geneva, WHO, 2002
[38] Ogden, J., Esim, S., Grown, C., Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus, Oxford University Press, 2006.
[39] Akintola, O., Gendered Home-Based Care in South Africa: More Trouble for the Troubled, African Journal of AIDS Research, 5(3): 237-247, 2006.
[40] Age, Gender and HIV., HelpAge International, London: Chapter 2, 2003

children—to comprehensive packages of services provided by government, NGOs, FBOs, CBOs, and the private sector.[41]

In Africa and other resource-poor settings family and community-centered care networks are often the key intersecting point for continuum of care services provided by hospitals and health facilities, support groups, and external referral services. A 2005 World Bank working paper surveying the challenges of community-based care delivery suggested that local linked service packages and referrals might include but are not limited to the following breakdown of shared responsibilities:[42]

- *Family and Community-Centered Care:* Nursing care, ART adherence, nutrition, children in need, socioeconomic, health education, spiritual guidance, psychosocial, housekeeping.

- *Hospital/Health Facility:* Diagnosis, care and treatment, specialist services, laboratory services and counseling.

- *External Referral Services:* Voluntary Counseling and Testing (VCT), PMTCT, pharmacy, social services, economic assistance.

- *PLWHA and OVC Support Groups:* Positive living, legal aid, income generation, support and counseling.[43]

Financial Costing of Family and Community-Centered Care Approaches

Assessing the cost benefits of family and community-centered care versus formal institutionalized care is difficult due to a lack of documented estimates and research on the subject. A 2005 study of funding flows conducted by the Bernard van Leer Foundation found that global HIV/AIDS funding is usually broken down under general line item headings such as "prevention", "care", "orphans support" and" research" with few if any categories for family or community care delivery. The study found no uniform reporting system and noted that most donors do not publish progress reports until after a one-year delay. When they do report, HIV/AIDS funding is often merged into broader categories such as "sexual and reproductive health" and there is little detailed breakdown of money spent or its impact in the field.[44] A 2005 ActionAid study discovered that the UK Department for International Development's (DFID) reporting system did not provide "a single accurate record of HIV and AIDS expenditure. Their expenditure statistics did not reveal the composition of interventions nor the reach by gender or to the

[41] UNICEF et al, The Framework for the Protection, Care and Support of OVC Living in a World with HIV/AIDS, New York, UNICEF, 2004.
[42] Gikonyo, Juliet, Mohammad, Nadeem, *Operational Challenges: Community Home Based Care for PLHWA in Multi-Country HIV/AIDS Programs in sub-Saharan Africa*, AIDS Campaign Team for Africa, World Bank, Africa Region Working Paper Series No. 88, August 2005.
[43] Ibid
[44] Dunn, A,, The Way the Money Goes: An Investigation of Flows of Funding and Resources for Children Affected by HIV/AIDS, Working Papers in Early Childhood Development, Young Children and HIV/AIDS sub-Series, Bernard Van Leer Foundation, 2005, p. 20.

poor and vulnerable," making it difficult to assess whether UK expenditure is sufficient or appropriately targeted.[45] In the report UK officials told Parliament "recording accurate expenditure on HIV and AIDS is difficult because of the cross-cutting nature of many initiatives and of the range of methods used to channel development assistance." Research by Save the Children in four Southern African countries echoed these same sentiments, stating that it is difficult to determine what proportion of funds donated for the support of children in need reaches the community level.[46] The report found that tracking AIDS resources from donors, government, INGOs and NGOs is a poorly developed or neglected priority in most SSA countries.[47] For example, researchers had difficulty identifying GF resources beyond national-level disbursements. This raises serious concerns about the accountability and impact of the funds provided and is incompatible with the GF's commitment to maintain transparent monitoring.[48]

The few studies that do exist indicate that program costs vary by rural vs. urban location, service packages, and program expansion and maturity. A study in Rwanda, for example, found that the home-based care approach has a higher estimated cost per client than community-based care, with monthly costs per patient ranging from approximately $31.20 to $36.01 compared to $12.75 to $24.53, respectively.[49] Scale and program maturity also impacts the cost of home-based care. Yet in Zimbabwe, the cost per home care visit decreased from US$10 to US$1 as the program expanded [50] because although costs increased by 31 per cent, the number of clients and visits also increased and the program became more efficient. Since the pandemic first arose in the 1980s, home-based care has always been looked upon as more accessible and affordable than hospital inpatient care. This is true for patients who are unable to travel to or pay for inpatient care, and for governments and donors who would otherwise have to pay the higher costs of inpatient health care facilities.[51] Notably, these costs increase in rural areas where a vehicle is required for staff/client transportation.[52]

In 2005 UNAIDS estimated the annual global costs of scaling up integrated health care for HIV/AIDS consisting of prevention, treatment and care to be US$12 billion, and is likely to double over the next 20 years.[53] This sum compares to annual global military expenditures of $852 billion in 1999, of which developing countries spent $245 million. The annual total cost of agricultural subsidies of OECD countries amounts to an

[45] Felicity Daly, M., Where's the Money? Towards Transparency in UK AIDS Expenditures, ActionAid, September 2005, p. 2.
[46] Foster, G., Bottleneck and Drip-Feeds: Channeling Resources to Communities Responding to Orphans and Vulnerable Children in Southern Africa, Save the Children, 2005.
[47] UNAIDS, Report on the Global AIDS Epidemic: 4th Global Report, Geneva, 2004.
[48] Taylor, N., Many Clouds, Little Rain: The Global Fund and Local Faith-Based Responses to HIV and AIDS, Briefing Paper 4, Tearfund: London, 2005.
[49] Chandler, R., Decker, C., & Nziyige, B., Estimating the Cost of Providing Home-based Care for HIV/AIDS in Rwanda, Partners for Health Reform Plus, 2004
[50] Lee, T., FOCUS Evaluation Report: Report of a Participatory, Self Evaluation of the FACT Families Orphans and Children Under Stress Program, Mutare, Zimbabwe; Family AIDS Caring Trust, 1999
[51] Ibid
[52] Uys L, Hensher M., The Cost of Home-based Terminal Care for People with AIDS in South Africa, South African Medical Journal, 2002;92:624-628
[53] UNAIDS, Report on the Global AIDS Epidemic, Geneva: 2004.

additional $300 billion.[54] Based on the numbers one might surmise that the issue of financing the expenditures to combat HIV/AIDS was not a question of affordability but rather a question of willingness by the national governments of affected countries, and of public and private donors, to pay for the costs of fighting HIV/AIDS.[55] In a 2006 investigation of estimated HIV/AIDS care and treatment scale up costs in 125 low-and-middle-income countries researchers found that preventing an estimated 28 million new infections would require investing about US$122 billion between 2005 and 2015—a sum that would reduce future needs for treatment and care. Analysis suggests that it would cost about US$3,900 to prevent each new infection, but that this will produce a savings of US$4,700 in forgone treatment and care costs. Analysts concluded that investments in prevention now would actually produce a net financial saving as future costs for treatment and care are averted.[56] Whether the global financial gatekeepers agree to reroute existing available funds to build integrated family and community-centered health care systems remains a primary question and challenge. Other JLICA reports have articulated the need for more focused cost analysis of the family-centered care approach, which by its very nature of addressing the needs of an entire household rather than only one member of the household, is likely to incur more costs.[57] Today in more than a dozen countries in Southern and East Africa governments and donors are redirecting health and social welfare funds to families and sometimes communities through direct salaries to unpaid care workers or through cash transfers, old age pensions or child-care grants targeting HIV-affected families. These monies, which double as a social protection safety net to help secure poor household's basic needs, are known to reduce household poverty and generate jobs while strengthening sustainable local technical capacity to continue coping with the pandemic.[58] Financial investments at the local level are known to help reduce the risks of HIV infection often associated with households living in poverty.[59]

The Socioeconomic Impact of ART Access and its Impact on the Family

A June 2008 UNAIDS/WHO/UNICEF report on global HIV/AIDS treatment announced that nearly three million people in resource-limited and middle-income nations are now receiving ART.[60] Given that family and community-centered care providers are often responsible for patient ART adherence, among many other health-related duties, there is

[54] OECD, Agricultural Policies in OECD Countries: A Positive Reform Agenda," OECD Policy Brief, Paris, 2003.
[55] Gillespie, S. et al, Scaling up Multi-Sectoral Approaches to Combating HIV and AIDs, Chapter 11, AIDS, Poverty and Hunger: Challenges and Responses, International Food Policy Research Institute, 2006.
[56] Stover, J., et al, The Global Impact of Scaling Up HIV/AIDS Prevention Programs in Low- and Middle-Income Countries, Science Express, February 2006.
[57] Dirks, R., et al, "Children Thrive in Families: Family Centered Models of Care and Support for OVC Affrected by HIV/AIDS, JLICA LG1, January 2008.
[58] Adato, M., UN Analysis Social de la "red de Proteccion Social' (RPS) en Nicaragua, International Food Policy Research Institute, Washington, DC, 2004.
[59] Zoll, Miriam, *Securing Orphan Access to Education by Compensating HIV/AIDS Workers for Their Unpaid Labor,* Presented at Oxford University's 8th Annual UKFIET International Conference on Education and Development: Learning and Livelihood, October 2005
[60] UNAIDS/WHO/UNICEF, Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector, Progress Report, June 2008.

significant value in investigating the socioeconomic benefits of successful treatments. In a 2008 study entitled, *The Economic Impact of AIDS Treatment: Labor Supply in Western Kenya,* the authors found that the provision of ART leads to a large and significant increase in the labor supply of HIV-positive workers. This increase occurs very soon after the initiation of ARV therapy: within six months, there is a 20 per cent increase in the likelihood of their participation in the labor force and a 35 per cent increase in hours worked during the past week. Parents or guardians' ability to resume labor has profound effects on younger children who are more likely to be able to return to school and who exhibit improved nutritional status.[61] The authors conclude that the private benefits of restored labor supply after treatment commences adequately covers the costs of treatment.[62]

Another new 2008 study published in the journal, *AIDS*, provides evidence showing that despite international concern about poor ART adherence in developing countries, African adults and now children receiving ART through a family-centered approach are exhibiting adherence patterns that exceeds that of their peers in the West.[63] Research conducted at the Sinikithemba HIV/AIDS clinic in South Africa documented the experiences of 151 children enrolled on highly active antiretroviral therapy (HAART). Eighty-nine per cent of cohorts reported greater than 95 per cent adherence, resulting in 84.0 and 80.3 per cent virologic suppression at six and 12 months.[64] In contrast, pediatric cohorts from the U.S. and Europe reported lower virologic efficacy ranging from 25 to 50 per cent attributed in part to lower adherence.[65] The research also showed that HIV-positive caregivers receiving HAART at the same treatment site may provide more informed treatment support for their children [and community members] which results in better ART adherence and outcomes.[66] These findings represent important paradigm shifts about perspectives towards HIV-infected families receiving ART. Rather than assuming that all HIV-infected households are being 'ravaged' or 'devastated', family-centered ART delivery and care can actually cultivate unity, continuity, knowledge, and strength for pediatric patients and other HIV-infected family members. The authors argue in favor of family-centered HAART treatment models in order to protect the integrity of caregiving structures and prevent the negative pediatric outcomes associated with the decline in the health or death of primary caregivers.[67]

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[61] Thirumurthy, H., et al, The Economic Impact of AIDS Treatment: Labor Supply in Western Kenya, The Journal of Human Resources, XLIII (3), Board of Regents of the University of Wisconsin System, 2008.
[62] Ibid.
[63] Reddi, A. and Leeper, S., Antiretroviral Therapy Adherence in Children: Outcomes in Africa, AIDS 22: 906 – 907, 2008
[64] Reddi, A., Leeper, S., Grobler, A, Geddes, France, K, Dorse, G., et al, Preliminary Outcomes of Pediatric Highly Active Antiretroviral Therapy Cohort from KwaZulu-Natal, South Africa, BMC Pediatr 2007; 7:13.
[65] Van Rossum, A., Fraaj, P., de Groot R., Efficacy of Highly Active Antiretroviral Therapy in HIV-1 Infected Children, Lancet Infectious Diseases 2002; 2:93-102.
[66] Reddi A et al. Antiretroviral Therapy Adherence in Children: Outcomes in Africa. AIDS 22: 906 – 907, 2008.

[67] Ibid.

Family and Community-Centered Care: Overview of Key Components of Success of Based on Four Case Studies from Kenya and Rwanda

The four programs highlighted in this report—AMPATH, CARE International's 5x5 Early Childhood Development and its Case Manager Pilot Program, both in Rwanda, and PIH-Rwanda—support a client/patient base of HIV-positive individuals and their families who often experience poverty, malnutrition and insufficient access to health care and education. Data for each of the case studies was drawn from internal and external descriptive and analytical program studies and reports. This includes third-party program evaluations, research and policy documents, conference abstracts, program monitoring documents, project descriptions, work plans and reviews. Personal interviews and email correspondence with project staff was also included. Research methodology for this report did not include direct field observations that would be necessary to most accurately characterize appropriateness, relevance, effectiveness, and program factors enabling or constraining intended intervention outcomes.

After careful review and comparison of available program data several key indicators and themes began to emerge that might explain the tremendous success of the programs featured. These common denominators and key indicators are:

- An overall program philosophy rooted in social justice and the right for all patients to have access to a broad range of health care services, regardless of their ability to pay.

- An adherence to a broadened definition of health care that extends beyond traditional medical treatment to also include the linked provision of nutritious foods and access to psychosocial support, education, economic security, legal protections, clean water and basic shelter.

- A program philosophy that believes children are best served by providing integrated health and social service support for the entire family, and that children between the ages of 0 and 8 benefit from early childhood development practices in daycare or home-based settings.

- A program architecture that revolves around the vital role of the Community Health Worker, who is highly trained, compensated and is sometimes HIV-positive her/himself.

- A sustainable, integrated food and nutrition component that is considered an essential patient right and is viewed as equally important as access to ARVs and other life-saving medicines. This is of particular concern today given the global rise of food and fuel costs and critical food shortages, particularly in poor countries and among poor families.

- A community-based comprehensive health care delivery system that links medical and social support services directly to patients and families in need, thereby

alleviating a significant burden of daily care away from overburdened health facilities in the formal sector.

- A strong commitment to hiring from within the community, a strategy that not only enhances ART adherence and program-patient relations, but also benefits families and communities by creating jobs, helping to reduce local poverty and serving as an HIV prevention tool.

- A program focus that cultivates ongoing participatory and reciprocal partnerships between a range of actors, including community leaders and members, local social and economic resource providers, and district and national level government agencies, all of who are invested in the success and sustainability of the program.

- A cross-disciplinary approach to managing health care delivery through new and expanded partnerships at the government level (and at the department level within academic settings). For example, instead of enlisting only the support of the Ministry of Health, enlist support across government agencies to include Ministry of Finance, Ministry of Agriculture and Ministry of Education.

- A management style that is transparent, experimental and flexible.

- Large infusions of operating costs provided by external donors, such as PEPFAR, the Clinton Foundation and the GF for a minimum of five years.

Chart 1: Types of Family and Community-Centered Care Offered by AMPATH, CARE and PIH.

Service	AMPATH	CARE 5x5	CARE Case Manager Program	PIH
Economic Assistance	X	X	X	X
Nutrition Support	X	X	X	X
Compensation to workers	X	Not known	Pays some workers	X
Human Rights-based approach	X	X	X	X
Prioritization of ECD		X		
Psychosocial	X	X	X	X
PMTCT	X	Not known	Referrals	X
General Health	X	Referrals	In some cases	X

and HIV/AIDS, TB			and through referrals	
Hires or pools unpaid care workers from community	X	X	X	X
Educational Assistance	X	X	X	X
Jobs/Training	X	X	X	X
Pediatric AIDS	X	Referrals	Referrals	X
ART Access and Adherence	X	Referrals	X	X
Referrals and Linkages	X	X	X	X
Offers training to paid and unpaid workers	X	Not known	X	X

While all of the points highlighted above are vital for continued success, nutritional supports to HIV-affected households, early childhood development practices and remuneration to unpaid care workers are vital to program effectiveness and comprehensive care.

Nutrition

Chronic hunger, malnutrition and poverty pose huge health risks to children and adults in any setting but it poses a far greater danger to HIV-positive patients dependent on ARV treatments that require proper nutrition in order to be effective. Research shows that the health of female caregivers, particularly mothers, grandmothers, older sisters and aunts, has a significant impact on household welfare indicators, including child nutrition status. The deaths of adult women is known to heighten household food insecurity, decrease opportunities for children to attend school, increase the burden of work for remaining household members, and increase household poverty.[68] The few empirical studies available on the impact of prime-age adult mortality on agricultural production and income indicate that the effects are more severe among households that were relatively poor to begin with.[69] These households appear to suffer the most after incurring an AIDS-related death because they are less able to cope with the economic and social shocks that it generates. These results carry obvious heavy implications for family food

[68] Case et al, 2003 – find full citation
[69] Drimie, S., *HIV/AIDS and Land: Case Studies from Kenya, Lesotho and South Africa*, Report for Southern Africa Regional Office of the Food and Agricultural Organization, Human Sciences Research Council, Pretoria, South Africa, 2002. See also

security and nutrition for the poor in particular.[70] In 2005 USAID, the Food and Nutrition Technical Assistance Project and the Republic of Kenya conducted research at 13 government and non-governmental facilities in five sites—Nairobi, Thika, Kiambu, Eldoret and Mombasa. The study showed that most ART programs were singly focused on drug distribution but not other essential companion aspects of care, including food and nutritional needs. Few programs exhibited an integrated nutritional component or nutritionist, though health care providers indicated such access as vital to the success of the treatment and vitality of the patient and his/her family. The study found that food assistance to insecure households was critical to the effective uptake of ARVs and that more generalized public education about nutrition was lacking in communities.[71] Food assistance is often an expensive addition to HIV care and many programs lack funding necessary for targeting food security to HIV-infected patients and their dependents. Beyond the costs of growing food, there are additional expenses in managing large food donations. Significant investments are necessary for computer support systems, physical plant facilities, vehicles and dedicated program management and food distribution staff.[72]

Early Childhood Development

Early childhood, which encompasses birth to eight years, is considered by child development specialists to be the most critical foundation stage of growth and development. In the first two years of life a child's immune system establishes itself while the number of neural connection increase in the brain and nervous system. At the same time, nerves acquire myelin, leading to increases in gross and fine motor skill coordination. Poor nutrition and lack of affection and stimulation is known to create permanent deficits in children's physical, cognitive and socio-emotional lives.[73] Among children, it has long been recognized that nutritional deficiencies, such as the lack of vitamin A, iodine, iron, and inadequate caloric and protein intake, affect both physical and cognitive development. [74] Recent research shows that as many as 200 million children worldwide fail to reach their cognitive and socio-economic potential because of malnutrition, micronutrient deficiency, and lack of stimulation during early childhood.[75] These findings are especially pertinent for Africa where an estimated 15 per cent of orphans—6.5 million children—are under the age of five years. AIDS orphans and children who have experienced trauma early in their early years are more likely to

[70] Yamano, T. & Jayne, T.S., *Working Age Adult Mortality and Primary School Attendance in Kenya,* Department of Agricultural Economics, Michigan State University, East Lansing, MI, 2003.
[71] Thuita, Faith, Food and Nutrition Implications of ART in Kenya: A Formative Assessment, USAID, Food and Nutrition Technical Assistance Project, Republic of Kenya, February 2005.
[72] Mamlin, J. et al, *Integrating Nutrition Support for Food Insecure Patients and their Dependents into an HIV Care and Treatment Program in Western Kenya*, p. 11, 2007.
[73] Reinis, S., Goldman, J., The Development of the Brain, Biological and Functional Perspectives, Springfield, IL, Charles C. Thomas, 1980.
[74] Engle, P., Black, M., Behrman, J., Cabral de Mello, M., Gertler, P., Kapiriri, L., *Strategies to Avoid the Loss of Developmental Potential of More than 200 Million Children in the Developing World,* Lancet, 369 (9557), 229-242, 2007; Barrett, D., Frank, D., The Effects of Undernutrition on Children's Behavior, Food and Nutrition in History and Anthropology 6; NY; Gordon and Breach, 1987.
[75] Grantham-McGregor, S., Cheung, S., *Development Potential in the First Five Years for Children in Developing Countries*, Lancet, 369: 60-70, 2007.

experience depression and other mental health problems later in life.[76] HIV infected children are particularly vulnerable, frequently exhibiting more developmental delays than uninfected children. HIV infection often undermines neurological development and increases nutritional intake requirements while decreasing nutrient absorption.[77] It has been widely recognized that meeting the needs of these very young children requires integrated interventions that move beyond the traditionally isolated realms of health and education to also encompass child rights, the economic empowerment of families, and improved community-care capacities.[78]

Hiring Local Caregivers Improves ART Adherence and Reduces Poverty

Two of the programs featured in this report—AMPATH and PIH—have since the inception of their programs in Kenya and Haiti more than two decades ago prioritized payment of their community health workers (CHW), many of whom are poor women. Their decision to compensate workers appears to be both philosophical and pragmatic. Devoted to ensuring the dignity and human rights of all patients and workers, both programs also recognize the inherent value of retaining a trained, paid staff over the limitations of an untrained, unremunerated volunteer force. Dr. Robert Einterz explained AMPATH's decision in an April 2008 interview:

"I have yet to experience any system of care that thrives on voluntarism. There is a justifiable expectation of payment on the part of virtually every health worker with whom I have worked in each of these countries (U.S.A Haiti, Kenya). I do not think we should expect a mother living on the edge to consistently devote her energy and talent to caring for others while her children are living in poverty. From an economic development perspective, I think it is irresponsible to consider the delivery of a health care service as having no monetary value. In sum, I think there is a moral, economic, and medical imperative to compensate heath workers." [79]

Program literature articulates the view that hiring from within the local community is an essential poverty alleviation strategy and an opportunity to spawn local job creation. Understanding that sustained productivity and financial compensation to workers and cash transfers, old age pensions or child welfare grants to family caregivers are related, AMPATH states that it is working hard to determine the best ways, including financial incentives, to maximize the efficient and effective delivery of services through local communities. It has found that relatively small salaries—where none previously existed––wage increments, and/or incentives can be powerful motivators and can have a huge effect on empowering any given person (worker) and her family to achieve economic security.[80]

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[76] Segendo, J., Nambi, J., *The Psychological Effect of Orphanhood: A Study of Orphans in Rakai District,* Health Transition Review, 7, Bartlett, K. and Mimanyi, L., 2002.
[77] Arpadi, S., *Growth Failure in HIV- Infected Children, Durban,* WHO, Department of Nutrition for Health and Development, 2005.
[78] *Promoting Early Childhood Development for OVC in Resource Constrained Settings: The 5x5 Model,* CARE, USAID, Hope for African Children Initiative.
[79] Zoll, Miriam, Phone Interview with Dr. Robert Einterz, April 22, 2008
[80] Zoll, Miriam, Phone Interview with Dr. Robert Einterz, April 22, 2008

Paul Farmer, co-founder of PIH, echoed these same sentiments in a 2007 PloS Medicine Magazine article that asked the question: *Which Single Intervention Would Do the Most to Improve the Health of Those Living on Less that $1 Dollar Per Day*?

"Hire community health workers to serve them. In my experience in the rural reaches of Africa and Haiti, and among the urban poor too, the problem with so many funded health programs is that they never go the extra mile: resources (money, people, plans, services) get hung up in cities and towns. If we train village health workers, and make sure they're compensated, then the resources intended for the world's poorest—from vaccines, to bed nets, to prenatal care, and to care for chronic diseases like AIDS and tuberculosis—would reach the intended beneficiaries. Training and paying village health workers also creates jobs among the very poorest."[81]

CARE Rwanda, whose programs are also grounded in a human rights-based approach to care, compensates its case managers but does not have enough program funds available to pay its volunteer health force of more than 1000 workers. As is explored later in this report, CARE explained that the government of Rwanda prohibits direct compensation to caregivers, preferring instead to pool available funds in PLWHA cooperatives and support groups.[82]

[81] PloS Medicine Special Issue on Poverty and Health, "Which Intervention Would Do the Most to Improve the Health of the Extreme Poor?, October 22, 2007
[82] Zoll, Miriam, Phone Interview with Madhu Deshmukh CARE Rwanda Representative, May 2008.

Program Case Study 1: Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH)

Treating 50,000 HIV-Positive Kenyans and Providing Integrated Nutritional, Health and Social Support to Their Children and Families

AMPATH works throughout Western Kenya and enrolls 2,000 new patients per month.

In 2001 the Academic Model for Prevention and Treatment of HIV/AIDS (AMPATH) had only one HIV-positive patient enrolled in its program. Today the Nobel Prize[83] nominated medical NGO is one of Africa's premiere integrated health delivery models providing free ARVs to 50,000 HIV-positive patients at 17 sites[84], weekly food assistance to 30,000 through the operation of six local farms and annual prenatal care to 25,000.[85] Each month it enrolls 2000 new patients. In total, AMPATH offers free health

[83] Press Release, Indiana University, http://medicine.iupui.edu/kenya/introduction.html, weblink.
[84] Mamlin, J., et al, Integrating Nutrition Support for Food Insecure Patients and Their Dependents into an HIV Care and Treatment Program in Western Kenya, Indiana University School of Medicine, 2007.
[85] AMPATH Internal Document, Summary of Food Distribution/Nutrition Department, 2008.

care, ART, PMTCT, nutrition, education, and income generation programs, as well as jobs and agricultural training to more than 70,000 people living in Western Kenya.

AMPATH is a health program, not simply a delivery system for medical care. It began in 1990 as a partnership between the US-based Indiana University School of Medicine (IUSM) and the Kenyan-based Moi University School of Medicine.[86] It is operated under the auspices and direction of the Kenyan Ministries of Health and Education and in 2004 received its first infusion of PEPFAR funds. The partnership was formally merged when Moi University began to actively seek out expatriate clinical teachers and institutional partners to fill faculty gaps. At the same time, three general internists from IUSM with long-term volunteer experience were seeking to develop a relationship with an SSA medical school. Today, IUSM faculty members based in Kenya share with their Moi counterparts responsibilities for clinical care, community based education and service, teaching, and research. AMPATH literature openly states that throughout its first decade the Indiana-Moi partnership failed to respond systematically to the HIV/AIDS crisis. Its first patient in 2001 was a young Kenyan medical student dying of AIDS who inspired the two partner institutions to formulate a systematic response to the pandemic, an effort that eventually evolved into AMPATH. In only a relatively short timeframe AMPATH has become one of the largest and most comprehensive AIDS-control systems in SSA, providing a complete system of care that has been described as a model of sustainable development by the Kenyan and U.S. governments.[87] This 18-year partnership involves cross-collaboration among virtually all the major disciplines at both medical schools. Since 1997 several additional North American medical institutions have joined IUSM in a partnership called the America/sub-Saharan Africa Network for Training and Education in Medicine—ASANTE—that means "thank you" in Kiswahili. This consortium currently includes IUSM, Brown Medical School, Duke University School of Medicine, Lehigh Valley Hospital and Health Network, the University of Utah School of Medicine, and the University of Toronto Faculty of Medicine.

AMPATH reports that delivery of services is challenging and occurs in the public sector through hospitals and health centers run by Kenya's Ministry of Health, and through food distribution sites dispersed throughout the country.[88] AMPATH operating principles are anchored in its long-term partnership with the university and the government, and through respectful community engagement and mutual reliance. Like PIH, their comprehensive model of care goes beyond clinical expectations by also offering programs in education, economic assistance to help families pay for school, food assistance, HIV prevention and safe-sex-practices, counseling, income generation support and training, the integration of HIV-positive employees, and voluntary testing.

[86] Inui, T., et al, AMPATH: Living Proof that No One has to Die from HIV, SGIM National Meeting, Toronto, CA, May 18 2006.
[87] Tobias, R, *Testimony to U.S. Senate Foreign Relations Committee*, March 7, 2006.
[88] Mamlin, J., et al, Integrating Nutrition Support for Food Insecure Patients and Their Dependents into an HIV Care and Treatment Program in Western Kenya, Indiana University School of Medicine, 2007.

Local Food Production + Local Food Security = Successful ART:

AMPATH has learned through experience that food security and poverty reduction are essential components of successful ART and any meaningful long-range response to the pandemic in general. Depending on their geographic location, between 20 to 50 per cent of AMPATH's early patients—many of whom were widows with children—were chronically hungry and lacked essential food stocks.[89] Too ill to work, many were unable to cultivate their small farms or engage in outside jobs, leaving them and their children impoverished, malnourished and often unable to attend school. Patients often walked miles to AMPATH clinical sites to receive ART but many often refused treatment when they learned there were no nutritional supplements to ward off household hunger. AMPATH quickly realized that scaling up ART without a food and anti-poverty strategy would doom their efforts to bring quality health care to the poor and HIV-infected. Listening to its ART clients they learned that once poor people start taking ARVs, somewhere between three to six weeks later they will whisper in your ear, *"I am hungry, please give me something."* Once they receive ARVs and food support their health rapidly improves and six to twelve months later they will again whisper in your ear, *"Please help me get productive."*[90] Through these lessons, AMPATH has learned that ART treatment should concurrently "*pay attention to patient's stomachs, spirits and bank accounts*."[91]

In 2002 AMPATH created its first demonstration farm on 10 acres of land donated by a local high school. Today it operates six high technology, continuous irrigation and teaching/demonstration farms in Eldoret, Mosoriot, Turbo and Burnt Forest and produces 20 metric tons of fresh produce monthly. Known as the HAART and Harvest Institute (HHI) the farms serve a dual purpose of teaching small landowners how to produce greater crop yields while providing nutritious foods to patients and families in need.[92] HHI serves as a focal point and a gathering place where persons living positively with HIV/AIDS can engage with the greater community. The farm also provides the community with greater ownership of its response to the HIV epidemic and helps slash stigma in the community.[93] Collectively these farms produce more than 5 tons of fresh food stock per week that provide a balanced diet of proteins, carbohydrates, fats and essential vitamins for all patient households for a minimum of at least six months. The WFP and USAID complement the fresh produce with enough donations of corn, beans,

[89] Einterz, R., Kimaiyo, S., Mengeck, Hl, Khwa-Otsyula, B., Esamai, F., Quigley, F., Mamlin, J., Responding to the HIV Epidemic: The Power of an Academic Model, Academic Medicine, Vol. 82, No. 8, August 2007.
[90] Mamlin, J., et al, "Integrating Nutrition Support for Food Insecure Patients and their Dependents into an HIV Care and Treatment Program in Western Kenya, p. 9, 2007.
[91] Food Assistance Initiative for ART Clients in a Rural Setting: The AMPATH-HHI Pilot Project, Mosoriot, Edoret, Kenya, no date.
[92] Kimaiyo, N., Lewis, S., Siika, A.M., HAART n' Harvest Initiative: Addressing Nutritional Needs of HIV-Positive Patients, Power Point Presentation, Eldoret, Kenya.
[93] Einterz, R., Kimaiyo, S., Mengeck, Hl, Khwa-Otsyula, B., Esamai, F., Quigley, F., Mamlin, J., Responding to the HIV Epidemic: The Power of an Academic Model, Academic Medicine, Vol. 82, No. 8, August 2007.

corn/soy blend, and oil to provide for 30,000. AMPATH purchases up to 3,000 eggs per day from chicken houses managed by its own patients, thus contributing to local and household economic security.[94]

Several years ago an assessment of AMPATH's HHI farm and its nutritional programs was conducted jointly by departments at Moi and Indiana Universities, and by Appropriate Grassroots Interventions, an NGO. It found that HHI not only generated a broad range of food stocks in a sustainable manner but that its agricultural techniques were environmentally sound as well. The horticulture department produces kale, cabbage, spinach, pumpkin, cucumber, onions, garlic, ginger, capsicum, beetroot, carrots, French beans, coriander and various other local vegetables. The fruit division produce includes lemons, oranges, mangoes, bananas, pineapples, guavas, loquats, custard apples, passion fruit, tree tomatoes and local and exotic herbs. The dairy department maintains one calf per year and milk lactations of over 6000 liters per cow. Ninety per cent of the raw milk is pasteurized and processed into maziwa lala (fermented milk), which contains lactobacillus acid that improves digestion and increases the shelf life of milk.[95] All milk packets bear HIV/AIDS educational information and the containers are re-used and filled with compost and a nitrogen-fixing tree that is then transplanted to patient's homes. Cow manure is incorporated in the compost pit to improve soil structure and fertility. Sespania trees are utilized as restoration crops providing high quality digestible crude protein leaves and nitrogen fixation to the soil. The cow manure, urine and rain roof catchment's water are stirred into a homogenous state and converted into bio gas for cooking providing up to two hours of cooking fuel per day. Each farm has a poultry department housing up to 500 chickens per farm.[96]

Number of Patients Receiving Nutritional Support from AMPATH and WFP

AMPATH currently provides health and social service support to approximately 50,000 HIV positive patients in 19 clinics throughout Kenya's North Rift, Western and North Nyanza Provinces. Approximately 20–50 per cent of all AMPATH patients are food insecure. To meet the needs of food insecure patients and their household members AMPATH in partnership with the WFP in 2005 began to offer additional nutrition support through the provision of maize, pulses and vegetable oil. Since the WFP food basket was added to AMPATH's HHI farm fresh produce, there has been an improvement in patients' adherence to treatment, improved quality of life, stigma reduction, and empowerment of patients and caretakers toward sustainability.[97]

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[94] Mamlin, J., et al, "Integrating Nutrition Support for Food Insecure Patients and their Dependents into an HIV Care and Treatment Program in Western Kenya, p. 9, 2007.
[95] Siika, A.M., et al., AMPATH's HAART 'N Harvest Initiative: Addressing the Nutritional Needs of HIV-Infected Patients on ART, Department of Medicine, Moi University, Appropriate Grassroots Interventions, Department of Food and Nutrition, Moi Referral Hospital, Department of Child Health and Pediatrics, Moi University Faculty of Health Sciences and the Department of Medicine, Indiana University School of Medicine.
[96] Ibid
[97] Einterz, R., Kimaiyo, S., Mengeck, Hl, Khwa-Otsyula, B., Esamai, F., Quigley, F., Mamlin, J., Responding to the HIV Epidemic: The Power of an Academic Model, Academic Medicine, Vol. 82, No. 8, August 2007.

According to AMPATH internal documents between October 2006 and March 2007, increased food donations from WFP/USAID allowed the number of beneficiaries enrolled in AMPATH's nutrition program to expand. [98]

- WFP currently provides AMPATH with enough food to feed 30,000 beneficiaries.
- 510MT of WFP food was distributed and has been feeding an average of 10,250 WFP beneficiaries monthly.
- WFP has given AMPATH permission to implement a pilot nutrition program to feed 1,400 beneficiaries specifically targeting children in need in HIV/AIDS-affected homes without an AMPATH patient.
- USAID provided enough food to feed 2,000 beneficiaries at one AMPATH clinic site.
- 8 nutritionists, 14 food distribution workers and 2 food distribution supervisors serve the program beneficiaries at these new sites.
- AMPATH was able to construct or renovate temporary rooms to distribute the food.
- Within all AMPATH clinic sites a total of 13,304 patients received nutrition counselling.

Nutritional Testing

All HIV-infected patients undergo comprehensive nutritional assessments and those found to be malnourished or food-insecure are given nutritional counseling and a nutrition prescription for the entire household. A patient must meet a combination of the following factors for his/her family to become a beneficiary of food assistance: BMI <19, CD4 <200, poor economic status and household food insecurity.[99] Patients that meet the above criteria receive monthly prescriptions for full nutritional support for themselves and all dependents that live in the same house and eat from the same pot. Patients present food prescriptions at the HHI farms or food distribution sites scattered throughout the region. In 2007 AMPATH nutritionists assessed over 130,000 patients and their dependents for food insecurity (75 per cent female, 85 per cent aged 19 and older), counseled 61,535 of them about nutrition, and enrolled 9,623 new patients onto the food program, including an average of three dependents per patient.[100] The assessment includes documenting the patient's anthropometrics, clinical symptoms, economic status, most recent food intake, and food security indicators. Patient weight is documented each month and a progress note is written and stored in medical files.

All AMPATH patients and their dependents are enrolled on food support for an average of six months. By that time, the restoration of the immune system through ART allows many of them to reclaim their responsibility of providing food for their households. If they are unable to do so, they can enroll in one of AMPATH's specialized agricultural or economic training programs. AMPATH also provides assistance and supports to patients

[98] AMPATH Internal Document, Food Distribution and Nutrition Departments, 2008.
[99] AMPATH Internal Document, Nutrition Assessment Criteria, 2008
[100] Mamlin, J., et al, "Integrating Nutrition Support for Food Insecure Patients and their Dependents into an HIV Care and Treatment Program in Western Kenya, p. 9, 2007.

that are physically able and have good nutrition status but suffer from malnutrition due to poverty. These patients are visited at home by a social worker that confirms the economic status and food insecurity of the household and grants permission for enrollment.[101] Each patient enrolled on nutritional support through the rural clinics in Mosoriot, Turbo and Burnt Forest *owns* and manages a one square yard garden that requires no special expertise, expensive equipment or significant investments. The patient and his/her family learn how to grow and manage their own food and later transfer these skills to their own garden at home.

AMPATH's Commitment to Economic Security

Family Preservation Initiative

The vast majority of AMPATH's early patients were AIDS widows who did not have the capital or skills necessary to support their children. It became obvious to AMPATH early on that if their program was to be sustainable and successful, economic security and food security needed to be equally prioritized. In response to this need the Indiana-Moi partnership created the Family Preservation Initiative (FPI) that now operates at 10 sites. FPI provides skills training, micro-credit, agribusiness support, a fair-trade-certified crafts workshop and agricultural cooperatives to recovering patients rebuilding their lives as healthy HIV-positive citizens.[102] The program works to permanently lift patients and their households out of extreme conditions of poverty by supporting overall health and encouraging food and economic self-sufficiency. It also fosters a culture of savings that encourages self-sufficiency and improves families' ability to plan for the future. Research links increased household income directly to improvements in individual and child health, and translates into improved child nutrition, increased school performance and a greater sense of wellbeing and happiness.[103]

Micro-credit Program

Though savings opportunities are particularly important to very poor households, families living in poverty are often viewed as being "too poor to save." As a result, very few formal institutions target the poor with accessible, affordable, secure savings opportunities for the benefit of vulnerable households and children. While individual savings products would ultimately best serve the needs of poor children and caregivers, cost and infrastructure constraints often prevent their accessibility. Through experience, AMPATH has found that savings creates a sense of empowerment and helps households

[101] Ibid
[102] Yam, Venus, *Breaking the Cycle of Between Poverty and HIV/AIDS: The Role of Economic Interventions in an HIV Care Program*, Center for International Health, University of Toronto, October 11, 2007, DRAFT.
[103] Ibid.

meet their day-to-day needs and cash requirements for education, health care and the absorption of additional children into the household.[104]

AMPATH provides economically vulnerable patients with loans to boost the performance of their businesses. Incorporating key elements of the Grameen banking system, five to six clients from the same region form groups with assistance from FPI's business development officer and CHWs. Members of the group pool and accumulate savings while they receive business-training, and then two members are selected by their peers to receive loans of up to US$75. After two months time and a prompt repayment cycle, two more loans are dispersed to additional members of the group.[105] As of August 2007, 531 clients had acquired savings through FPI and 242 had received loans, with a repayment rate of 87 per cent at all ten sites. Though FPI initially distributed large loans of 10,000-20,000 Kenyan shillings (US$150 to $300) it quickly discovered that patients often diverted designated funds away from their intended business investments in order to pay for basic necessities such as food. Recognizing this as an underlying symptom of chronic food insecurity with negative impact for ART, FPI initiated an additional food distribution program and a smaller loan system that includes poultry and food supplier loans. As a result of this integrated response, patient loan repayment rates quickly soared from four per cent to 56 per cent. [106]

Agricultural Initiatives

Amkatwende means "*rise up, let's go*" and is the name of AMPATH's rural cooperative economic initiative. After identifying vulnerable patients, community-based social workers invite them to farm higher value crops, such as passion fruit and soybeans, two of AMPATH's staple food stocks. The program's success lies in its ability to improve small farmer agricultural yields and generate greater profits.[107] Paying a registration fee of US$15, HIV-positive farmers who have regained their health attend training programs to learn how to rear the new crop inexpensively and through sustainable means. For example, maize that is harvested only once averages only a half acre-yield and commands on average 350 Kenyan shillings per month. Passion fruit, on the other hand, provides a weekly harvest for approximately five years. Though passion fruit farming requires a higher level of initial capital, preparation and maintenance, it ultimately generates 5000 Kenyan shillings per month for every half acre. Soybeans, which are less labor intensive, are harvested every three to four months and generate monthly revenues of 3500 Kenyan shillings for every half-acre. Strengthening collective and individual savings that help buffer against unexpected life demands or climate hazards is a key project component.[108]

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[104] USAID, Save the Children & Academy for Educational Development, *Economic Strengthening for Vulnerable Children: Principles of Program Design and Technical Recommendations for Effective Field Interventions*, p. 22, February 2008.
[105] Yunis, M., Jolis, A., *Banker to the Poor: Micro-lending and the Battle Against World Poverty*, New York: Public Affairs, 1999.
[106] Ibid
[107] Yam, Venus, *Breaking the Cycle of Between Poverty and HIV/AIDS: The Role of Economic Interventions in an HIV Care Program*, Center for International Health, University of Toronto, October 11, 2007, DRAFT.
[108] Ibid

The program has helped to offset patient income loss due to AIDS and also to global and national agricultural policy that dictates crop selection. Agricultural research indicates that structural adjustment policies mandated by International Financial Institutions (IFI) in the 1990s derailed many eastern and southern African governments' efforts to implement state-led maize promotion policies. These programs featured pan-territorial producer prices, major investments in marketing board buying stations in small holder farming areas, and subsidies on fertilizer distributed on credit to small farmers along with hybrid maize seeds. Over time, maize marketing policies in Kenya, Malawi, Zambia and Zimbabwe, among other countries, were either eliminated or scaled-back significantly as part of economy-wide structural adjustment programs. These policy changes clearly reduced the financial profitability of growing maize in the more remote areas where maize production was formerly buoyed by pan-territorial pricing, and has shifted cropping incentives toward other food crops.[109]

FPI Managed Enterprises

Hiring from within the local community FPI manages three enterprises that focus on sustainable income generation opportunities for patients and families enrolled in AMPATH's programs.[110]

Imani Workshops: Prepares and trains HIV-positive recovered patients to reenter the workforce with marketable skills. It produces high-quality Kenyan crafts and clothing for local, regional and international markets. An urban-based endeavor, it provides a specific period of employment for 90 to 100 workers, most of whom are single mothers who have been separated from their families due to death or HIV-related stigma. *Imani* produces a variety of products, reusing and recycling materials when possible.

Cool Stream Restaurant: The restaurant provides a direct market for the agricultural goods produced by AMPATH patients. Situated near the Moi Teaching and Referral Hospital, *Cool Stream* provides meals and catering services for visitors as well as for AMPATH and university employees.

Poultry: FPI is responsible for the egg production division of AMPATH's food distribution program. At four sites, it produces its own poultry feed for more than 1900 chickens that lay more than 45,000 eggs each month.

A Family-Centered Linked Approach to Reaching Children in Need

[109] Jayne, T., Villarreal, M., Pingali, P., and Hemrich, G., *Interactions Between the Agricualtural Sector and the HIV/AIDS Epidemic: Implications for Agricultural Policy,* Agriculture and Development Economics Division, The Food and Agriculture Organization of the United Nations, March 2004.
[110] Yam, Venus, *Breaking the Cycle of Between Poverty and HIV/AIDS: The Role of Economic Interventions in an HIV Care Program*, Center for International Health, University of Toronto, October 11, 2007, DRAFT.

[Note: Unless otherwise cited, the information in this section was gathered through written correspondence with Tomeka Peterson, a Kenyan-based staff member of AMPATH's OVC Program].

AMPATH's OVC program is grounded in a multi-disciplinary approach to care and treatment focused on strengthening the capacity of families and communities to care for and protect children by prolonging the lives of all HIV infected family members and improving household self-sufficiency. Like many programs balancing budgets with the desire to serve, AMPATH must contend with the difficult task of identifying children and households it considers to be most in need of a range of support services, including food and nutrition, education, health care, child protection, psychosocial support, housing, and economic security. Assisting children within a family-centered rather than a specific orphan-centered approach to treatment, provision and care helps ensure that all family members receive a wide array of linked health-related and socioeconomic services.[111] Information sent to JLICA shows that AMPATH initiated its orphan's program in 2006 with funds from USAID, PEPFAR and private philanthropy and is now offering services to at risk children in four sites: Eldoret, Mosoriot, Burnt Forest and Turbo. In 2007 the Abbott pharmaceutical company began providing funds through June 30, 2008 for salary and training support of a pediatric outreach program in Port Victoria. As of April 2008, AMPATH had enrolled more than 9,000 children in its program. The total budget for all five sites is currently US$305,000. While AMPATH has been overwhelmed with demands for support within the current five funded sites, this same demand goes unmet in the remaining thirteen catchment areas. AMPATH hopes to expand this program to the remaining sites with the aim of serving 40,000 orphans and other children in need.

The communities AMPATH serves help formulate and maintain various aspects of the program and map out long-term plans for sustainability. Community members identify children and caregivers in need of assistance and services, recommend CHW candidates and help identify land that can be cultivated for crop production. As an entry point into more community engagement, AMPATH utilizes existing local structures such as chief barazas (meetings), churches, schools, and hospitals. It also partners with government agencies and FBOs to provide basic needs to children and their families.

Building Local Family ad Community-Centered Child Care Teams

Staffing

Social Workers: Ten AMPATH clinic social workers work closely with two pediatric program coordinators serving the five sites. Clinic based social workers provide referrals and support services to HIV-positive children, serve as a liaison with the program coordinator based in Eldoret, and supervise and coordinate all CHW community and home-based activities. They also facilitate trainings and meetings, mobilize community resources, ensure accountability of petty cash and emergency/medical funds, receive

[111] Sherr, Lorraine, Strengthening Families Through HIV/AIDS Prevention, Treatment, Care and Support: A Review of Literature, Joint Learning Initiative on Children and HIV/AIDS, 2008, p. 41

referrals from medical staff and provide follow-up on any medical or social issues that arise within families utilizing an AMPATH clinic. Typically a social worker meets with the parent/guardian to determine if a child needs to be referred to the program. Once a referral is made, social workers are responsible for gathering information for a baseline assessment regarding the child's name, location, age, sex, school enrollment status, guardian information, household income, and food security.[112]

CHWs: The program utilizes 68 paid CHWs who are based in the communities in which children and their families live. CHWs receive in-depth training in nutrition, pediatric adherence, counseling and testing, and assessing the needs of families.[113] They identify children in need in their home and/or community environments and advocate for and provide support to children in HIV-affected homes. Upon initial contact with the child or family, they assess food security, socioeconomic status and needs, family history, education history, safety and mental health screening. When the child is also HIV-positive, they assess adherence to ART and clinic appointments. Their close proximity to the family and frequent home visits minimize loss to follow-up, and ensure that children in need receive proper general medical services and referrals to AMPATH and other community based services as needed. Children and families are re-assessed periodically to ensure that new needs are being met. All identification and assessment information and services provided are documented and entered into a database.

Other Staff Positions: AMPATH clinics serve as the main clearinghouses for identifying new patients and rely on referrals from clinic staff to the social workers or through a CHW based in the community where vulnerable children and families lives. Additional staff positions filled by local community members include Traditional Birth Attendants (TBA), Community Owned Resource Personnel (CORP) and Community Health Extension Workers (CHEW). Eligible children are assigned an identification number to assist staff in monitoring the type of services administered. To enroll in the program, AMPATH requires a copy of a death certificate stating the cause of parental or caregiver death as HIV/AIDS, or a copy of the parent/guardian's AMPATH identity card.[114]

Referrals and Links

The AMPATH OVC program team receives referrals from the community and also makes referrals to community-based resources. Staff members actively participate in meetings convened by Kenyan governmental officials, including the Children's Officer of the Children's Department, the Ministry of Education and the Department of Social Services. AMPATH social workers will make referrals and write petitions to the Children's Officer when a child may need to move to a safer living environment. Social workers also work closely with the Center for Assault Recovery in Eldoret, which provides medical care and psychosocial support to rape survivors. The OVC department has also assisted children with referrals to Moi Teaching and Referral Hospital for minor

[112] Ibid
[113] Ibid
[114] AMPATH Internal Document, OVC Program, 2008, correspondence with Tomeka Peterson, Kenya, 2008.

surgeries and other medical services. There are a few residential children's homes within the community that provide shelter and care for HIV-infected children attending AMPATH clinics. Social workers collaborate with the matron of the home to help meet children's nutritional, educational and psychosocial needs.

Services and Numbers of Children in Need and Families Served

AMPATH's OVC program provides a wide-range of services that include health care, nutrition support, educational assistance, shelter, protection assistance, agricultural assistance, referrals to FPI, like skills seminars and psychosocial supports.[115] These services are provided to HIV-infected and affected children within five clinic areas.

Health Care: All HIV-infected children receive health care services including medications, follow-up of missed medical appointments, and ART adherence intervention through an AMPATH health clinic within their catchment area. If a child has additional medical needs, AMPATH provides assistance if no other community resource is available.

Nutrition Program: This specific food assistance program is targeted to children in families that do not have an AMPATH patient living in the home. Eligibility for food assistance is determined by a scale rating which determines most needy based on a score according to a variety of indicators. These include head of household status (child-headed, elderly, single-parent, bedridden, etc), economic status, monthly income level, food access, and number of dependents.

All children enrolled in the nutritional pilot program are weighed and measured by a clinical nutritionist at an AMPATH site during their initial visit, and then again during the months of April, August and December. Beneficiary families receive food support for twelve months. During that time, trained social workers and CHWs provide the family with guidance to hep determining the best way for them to become food secure. Between October 2006 and March 2007:

- AMPATH provided on average 6,356 children with nutrition support each month.
- An average of 6,086 needy children (3,121 girls and 2,965 boys) benefit monthly from maize, beans and vegetable oil provided by WFP.
- An average of 420 children in need benefit monthly from food provided by USAID.

Educational Assistance: AMPATH supports vulnerable children's enrollment in school from pre-unit through secondary levels and provides eligible children with assistance for school fees, and other education supplies. Each AMPATH clinic site has a small staff committee that meets periodically to review school fee request applications. The committee consists of the social worker, clinical officer, nutritionist, outreach worker, and other delegated clinic staff. School fee assistance may be requested for pre-unit, secondary, poly-technical colleges and in a few special cases for primary education.

[115] Ibid.

AMPATH also provides impoverished FORM I students with basic needs such as mattresses, blankets, and clothes, including school uniforms. The family provides the child's measurements and samples of the fabric to be used in making the uniform. A request is then sent to the FPI *Imani* Workshop where PLWHAs receiving training in tailoring construct the uniform. The finished uniform is then delivered to the family.

Shelter and Care: AMPATH provides clothing, shoes, blankets, mattresses, soap, and shelter renovation assistance to those in need. Young women also receive sanitary towels to enable them to remain in school during their menses.

Protection Assistance: When a parent(s) dies, some children may be chased from their homes and farms by relatives or community members seeking to claim the property as their own. Other children are sometimes left alone on idle land without adult supervision or proper equipment to cultivate crops. In such cases AMPATH social workers may refer child neglect and abuse cases to the local Children's Officer of the national Children's Department for safer placement of the child. They may also refer children and caregivers to a shelter for temporary placement or enroll them in AMPATH's FPI or agricultural training programs.

Agricultural Assistance: In 2007, AMPATH provided 86 vulnerable families with maize seeds and fertilizer to help stabilize household agricultural production and financial security. Some families became food self-sufficient enough to leave AMPATH's broader nutrition program while others used additional agricultural income to pay for school expenses and other basic necessities. AMPATH anticipates 1200 needy households will benefit from maize seeds and fertilizer assistance in 2008, the first year each family will agree to accept a loan of approximately 9000 Kenyan shillings worth of supplies, enough for one acre of land. The family will sign a contract stating their intent to repay the loan in the form of bags of maize after harvest. AMPATH's FPI office is currently negotiating with WFP to purchase patient-produced maize, a negotiation that would help small farmer's economic security and enable them to provide nutritional support to other program beneficiaries.

Referrals to FPI for Economic Sustainability: AMPATH's FPI program aims to teach and foster skills development to enable patients and their families to be productive, independent citizens. FPI provides training in tailoring, beading, pottery, papermaking, metal work, and business education courses. All FPI participants are taught basic skills in record keeping and savings to enable them to sustain themselves economically after graduating from the program. FPI provides agricultural extension services at eight AMPATH sites and offers simple farming techniques and knowledge about passion fruit, soya and locally available fruits and vegetables. To assist families in becoming self-sufficient, food beneficiaries may join a FPI farm cooperative that actively finds markets to purchase produce grown on individual family farms.

Life Skills Seminars: AMPATH provides one-day Life Skills Seminars to secondary school fee beneficiaries, including children in need. Its community mobilization department has been instrumental in facilitating discussions with adolescents that

encourage them to make healthy life choices, including knowing their HIV status through voluntary testing.

Psychosocial Support: At the Moi Teaching and Referral Hospital clinic, a special group of young adult HIV-positive patients meet with the social worker and adherence nurse to share their stories and concerns about their status.

Numbers Served

Information sent to JLICA from the Kenya-based OVC division states that every eligible child within AMPATH catchment areas have access to education, protection, shelter, food security, psychosocial support, medical care and economic security. Since March 2007: [116]

- Number of HIV-positive children receiving other medical care: 3,602
- Number of children receiving other medical care: 6
- Number receiving food (all beneficiaries under age 18): 13,205
- Number of households benefiting from nutrition support: 4,005
- Number of children in need receiving uniforms: 2,379
- Number receiving school fees: 416
- Number receiving secondary school fees: 289
- Number receiving pre-unit school fees: 69
- Number receiving vocational training: 10
- Number benefiting from agricultural assistance: 4,800
- Number benefiting from household items: 1,170
- Number benefiting from sanitary towels: 300
- Number benefiting from Life Skills Workshop: 129
- Number of children in need at Burnt Forest, Eldoret, Mosoriot and Turbo sites receiving at least one service in the area of education, community capacity building, basic needs, and economic/food security: 1,950
- Number receiving blankets: 140
- Number receiving mattresses: 60
- Number receiving clothing: 15
- Number receiving renovation of home: 4
- Number of families receiving monthly ration of soap: 50
- Number of children receiving emergency medical expenses: 10
- Total number of pediatric patients served: 10,498
- Total number of pediatric patients receiving ART: 2,311
- Total number of *children* enrolled in OVC social service program: 9,127
- Total number of *households* enrolled in social service program for children in need: 2,396

Major Lessons Learned and Program Challenges

[116] Ibid

In late 2005 AMPATH received funding from the Canadian-based Purpleville Foundation to conduct a series of program evaluations assessing work motivation, staff values, and suggestions and recommendations for program improvement. Staff, patients, village leaders, and officials from USAID and the Kenyan Ministry of Health and other government agencies were interviewed.[117]

Staff Suggestions: Interviews with 26 staff members in January 2006 revealed the following list of 15 commonly stated unmet needs and program challenges:

1. Expand services, especially to remote rural areas
2. Emphasize sustainability and economic development.
3. Provide more HIV prevention and screening.
4. Provide more individual and village education.
5. Strengthen institutional partnerships.
6. Improve efficiency and capacity at all AMPATH sites.
7. Improve records system.
8. Expand treatment to encompass a broader range of health conditions.
9. Improve programs for children.
10. Improve transportation among sites.
11. Focus more on at-risk populations.
12. Strengthen the role of Kenyan leadership in AMPATH activities.
13. Strengthen staff capabilities.
14. Expand performance measurement and evaluation.
15. Increase community engagement and mobilization.

Community Suggestions: Local community leaders situated in AMPATH site catchment areas echoed the same points and added three additional concerns:

16. Improve access, including transportation assistance.
17. Expand outreach to those who are too sick to proactively seek care.
18. Provide incentives (economic and otherwise) to strengthen village-based service delivery.

The evaluation noted that that village and patient perspectives seemed to place greater emphasis on certain improvements than would be apparent from staff. Community suggestions varied considerably from site to site with village participants expressing not only their preference for more community-based care and HIV and other education, but also strong confidence in their abilities to mount such services themselves, with AMPATH's assistance. Communities urged AMPATH to do more to reach men of all ages, referring to the tendency for men to be less engaged in HIV prevention and less able to discuss sexual traditions necessary for reducing HIV risk.

[117] Kyandiko, W., Inui, T., and Sidle, J., PVF Report II: How Can AMPATH Improve? Qualitative Analysis Team, Purpleville Foundation, Canada, March 31, 2007.

Patient Suggestions: The top request from 56 patients interviewed at five sites was economic assistance and nutritional supports.

Policymaker Suggestions: A third qualitative assessment was conducted with Kenyan-based policymakers in November 2007.[118] The content of the inquiry focused on office-holders' knowledge of AMPATH's record of rapid growth and recommendations for improvement. In the course of the evaluation, policymakers made reference to AMPATH's leadership and their ability to be flexible and make changes rapidly when required. Ministry of Health officials noted that AMPATH had hired existing medical officers from within the ranks of the MOH and that the program's decision to hire HIV-positive workers worked to its advantage. The 16 policymakers interviewed suggested the following improvements:

1. Assure AMPATH's sustainability.
2. Maximize AMPATH's unique contributions to all HIV programs in Kenya.
3. Conduct policy-relevant operations research.
4. Enhance local MOH site development.
5. Strengthen relationships to other programs in Kenya.
6. Communicate and disseminate information.
7. Strengthen relationship to MOH and other GOK leadership.
8. Develop less resource-intensive models of HIV care.

In terms of sustainability, policymakers raised their concern over the program's ability to sustain itself if the partnership between Moi and Indiana University ever dissolved. As one interviewee stated: *"All these supporting partners—when they leave will the system continue?"*[119] Discussion also turned to issues of equity and AMPATH's unique status as a highly effective and funded program among numerous other HIV-projects that are not as well resourced. A number of interviewees spoke about their concern that AMPATH's success was overshadowing other program's ability to be viewed as effective and that perhaps AMPATH should temper some of growth. As one policymaker framed it: *"Envy is a very powerful, and I think very destructive, negative emotion or human characteristic. So that is just a note of caution…I wish everything we were doing in every part of Kenya, much less the other 14 focus countries of the PEPFAR, was of the same quality that AMPATH offers, but it's not and it's not going to be in the foreseeable future."*[120] Another interviewee stated his concern that perhaps AMPATH should be doing less for any given individual but provide more general services to more people. *"I think their model is too good for what we can do from a public health stand point. So I'd like to see them do slightly less intensive services over an even broader geographic range."* A representative from the Kenyan AIDS commission recommended that perhaps *"it would be better if you pooled the money and it was available across the country and we made sure that everybody had access to basic investigations, rather than a particular*

[118] Inui, T., Nyandiko, W., Sidle, J., The AMPATH Program through Policymakers' Eyes: GOK and International Agency Perspectives on Program Growth and Need for Improvement, Purpleville Foundation, Canada, November 21, 2007.
[119] Ibid, p. 30.
[120] Ibid, p. 48.

program having access not just to investigations but also food…we should rethink how we are distributing the money that we have so that we go for things that would support the entire [national] program rather than making perfection out of some of the programs." AMPATH's response to these concerns was that "it would not pull back on what is was doing but would always try to improve and expand."[121]

[121] Zoll, M., Interview with Robert Einterz, May 2008.

Program Case Study 2: CARE's 5x5 Model in Rwanda: Promoting Early Childhood Development for Children in Need

CARE's 5x5 Model pilot program is specifically geared toward providing early childhood development (ECD) practices and integrated health-related services to children and families in need in Rwanda, as well as four other African nations. Comprehensive ECD programs are known to reduce childhood mortality, increase children's access to education and health care, improve the economic security of households, and build the capacity of communities to respond to the needs of children in need. Of the four programs featured in this report, the 5x5 program appears to be the only model intentionally streamlining ECD into general health-related service delivery to families affected by HIV/AIDS. CARE's program advances child-centered interventions in five areas: nutrition, child development, economic strengthening, and health and child protection. It engages the family and community at five different levels: the individual child, the caregiver or family, childcare settings, the community (including health services) and the national policy arena (particularly related to health and education). While the childcare setting is utilized as a primary entry point, the critical strength of the 5x5 approach is its ability to link numerous actors and services and to inspire strong investment in community ownership. [122]

CARE's Integrated, 5x5 Approach

The majority of information about this program case study is garnered from one CARE program report published in 2007, *Promising Practices: Promoting Early Childhood Development for OVC in Resource Constrained Settings: The 5x5 Model.* Program coverage addresses child-survival, ECD, food security, child rights, nutrition, economic security, education, support to child caregivers, community capacity building, and psychosocial supports. Since 2006 CARE has been working in partnership with USAID-Hope for African Children Initiative, the Centers for Disease Control, Emory University and the Bernard Van Leer Foundation to replicate the program, now operational in Rwanda, Kenya, Uganda, Zambia and South Africa. Prior to establishing the 5x5 Model, CARE staff reported significant gaps in services, treatment and care for the 0-8 year-old child-population in AIDS-affected households and communities. Cross-visits by staff between country offices revealed that this was a widespread problem in a number of SSA countries. Too young to be in school, staff found that many of these children were left unattended at home while overburdened caregivers were forced to choose between work and childcare responsibilities. First piloted in the district of Kamonyi, Rwanda, CARE is working with communities to establish and operate three ECD centers for children between the ages of two and four in Musambira, Karama, and Nyarubaka. It is also supporting two nursery schools for children aged four to six in Gacurabwenge and Karama.[123]

[122] Promising Practices: Promoting Early Childhood Development for OVC in Resource Constrained Settings: The 5x5 Model, CARE, USAID and Hope for African Children Initiative, 2007.
[123] Relief Web, Press Release, Covance and CARE Partner in Rwanda Early Childhood Development Initiative, Princeton, NJ, December 2007.

CARE began inserting ECD into its global early childhood education portfolio in the mid-1990s and today has more than 20 such projects worldwide. Like AMPATH and PIH, early on CARE realized that targeted health and education interventions were too narrow a scope for addressing the myriad, interdependent needs of very young children and families caught inside the multifaceted turmoil of the pandemic and its accompanying poverty. It also realized that singling out children, or children and their caregivers, did not adequately address the needs of the community or help catalyze necessary reforms in national policy toward young children.[124] The 5x5 Model helps build the capacity of childcare centers to facilitate ECD and education while simultaneously empowering caregivers and communities to improve the lives of young children in need and their families. The childcare setting—from crèche to formal school––is the critical entry point for intervention. Such settings provide cost effective opportunities to target and deliver integrated services to a broader number of children at once. After the child, the caregiver and the child's family are a central focus of program attention, with an emphasis on enhancing parenting skills and improving household economic security.

Program Structure: 5 Levels of Family and Community-Centered Integration and 5 Areas of Intervention

CARE's 5x5 model achieves high impact through 5 levels of integration in children's lives:

1. *Individual Child*: CARE measures the impact of its ECD interventions by regularly assessing children's physical, socio-emotional, and cognitive development.

2. *Caregiver/Family*: 5x5 provides caregivers and households with microfinance and income-generation training, adult education, parenting classes, mentoring, nutrition, child rights training and access to physical and mental health services.

3. *Child Care Settings*: Community child care settings make excellent gathering points for convening meetings, classes, and health services.

4. *Community, Including Health and Municipal Services*: Sustaining the benefits of ECD depends upon buy-in from caregivers, local authorities and community leaders. CARE partners with the community to deliver HIV education, reduce stigma and expand and accelerate referrals for HIV testing and treatment. In its efforts to improve community and family socioeconomic conditions, it also offers group savings and loans programs, income generating activities and training in small business management.

5. *The Wider Policy Environment with a Focus on National Ministries of Health:* Affecting national policy is integral to the heart of the 5x5 model. CARE is

[124] Promising Practices: Promoting Early Childhood Development for OVC in Resource Constrained Settings: The 5x5 Model, CARE, USAID and Hope for African Children Initiative, 2007.

> actively involved in strengthening government policy aimed at reaching the early childhood development objectives set forth in the Millennium Development Goals. Part of a coalition publicly advocating for the needs of children, CARE works to ensure that governments improve social protections for orphans, caregivers and HIV-affected families.[125]

The 5x5 Model also sets forth 5 areas of impact for comprehensive interventions necessary for helping young children in need survive and thrive:

1. *Food and Nutrition:* Numerous studies have shown the positive impact of proper nutrition on children's academic performance through their early years and adolescence.[126] The 5x5 Model prescribes that every ECD center should provide at least one nutritious meal to every child. Food is supplied through external and community food donations and through ECD center gardens. Centers producing their own food receive training in environmentally responsible farming techniques known to produce the most nutritious produce.

2. *Child Development*: Numerous research findings show that the physical, cognitive, and socio-emotional stages of child development are interrelated and interdependent. "Physical" stages refer to children's gross fine motor development, "cognitive" includes language and sensory development and "socio-emotional" addresses psychological and emotional development. Research from Bangladesh has found that psychosocial stimulation is equally as important for motor skill development as good nutrition,[127] and physical growth after the age of six has been shown to be highly dependent upon hormonal secretions triggered by affection and social interaction.[128] The 5x5 Model emphasizes the use of quality ECD curricula to build the capacity of teachers and caregivers to implement interventions alongside play and learning in child care settings. The governments of Kenya and Uganda now utilize country-specific ECD curricula and teacher training manuals, which are jointly produced by UNICEF and ministries of education. The most effective methods focus on verbal expression and learning through the five senses and through physiological movement. CARE works to improves staff and caregiver competency to help children transition from ECD centers to formal primary school, and to understand and identify child abuse and neglect.

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[125] Promising Practices: Promoting Early Childhood Development for OVC in Resource Constrained Settings: The 5x5 Model, CARE, USAID and Hope for African Children Initiative, 2007(?)
[126] Pollit E. et al., Early Supplementary Feeding and Cognition: Effects Over Three Decades, Monographs of the Society for Research in Child Development, 58:7, 1993.
[127] Hamadani, J., Huda, S., Khatun, F., Grantham-McGregor, S., Pyschosocial Stimulation Improves the Development of Undernourished Children, The Journal of Nutrition, Oct: 136, 10, 2006.
[128]Zeanah, C., Smyke, A., Koga, S., Carlson, E., (2005). "Attachment in Institutionalized and Community Children in Romania." Child Development. September/October: 76(5): 1015-1028. Fox, N., D. Johnson, et al. (2007). Findings from the Bucharest Early Intervention Project. Presented at the Better Care Network Symposium January 2007, Washington DC, George Washington University. Urban slum in Nairobi." Master's Thesis, Emory-Rollins School of Public Health.

3. *Economic Strengthening:* CARE employs a host of economic strengthening practices, including group savings and loan trainings, income generating activities and small business support. Savings and loan activities enable caregivers to save and lend at rates more reasonable than those charged by commercial banks. In many cases caregivers borrow money to start small businesses, often times those inspired through income generation trainings. Similar types of microfinance schemes have been known to have a positive affect on children.[129] Documentation shows that CARE's economic strengthening programs have succeeded in a number of SSA countries by increasing household income and assets and providing direct benefits to children in the form of better nutrition, increased school attendance and improved health care.[130]

4. *Children's Health:* Diarrhea, anemia, respiratory infections, malaria and malnutrition are some of the most dangerous threats to child survival. Additional research has determined that growth failure in children can be as much the result of emotional neglect as poor diet.[131]
   The existence of ECD centers helps improve children's health by encouraging and strengthening linkages between the centers and hospitals, health clinics, schools, and outreach service providers, as well as ensuring the completion of childhood vaccination regiments. By using ECD centers as vaccination sites, CARE helps to improve recordkeeping and monitoring of children's vaccine and health status. In rural areas ECD centers help identify, mobilize and link health workers to children and families' in need of greater support and services.

5. Children's Rights and Protection: The 5x5 Model leverages existing community resources to protect and advance children's rights through advocacy initiatives and trainings aimed at increasing awareness among local government authorities.[132] Ideally the 5x5 Model links existing legal services with ECD programming. CARE works to ensure that ECD staff members know how to access protection services and that community members understand how these services can assist them and the children they care for.

Rationale for Expanding ECD Program for HIV/AIDS-Affected Families

CARE's 5x5 approach integrates the critical developmental needs of orphans and vulnerable children between the ages of 0 and 8 who have experienced serious emotional trauma early in life, and who, research finds, are more likely to suffer from depression

[129] Navajas, S., Credit for the Poor: Micro-Lending Technologies and Contract Design in Bolivia, PhD Dissertation, Ohio State University, 1999.
[130] Lessons Learned, An Initiative Supporting the Basic Income Needs of HIV/AIDS Affected Households and Individuals, Kenya and Zimbabwe, SIMBA, CARE, 2004.
[131] Johnson, D., Medical and Developmental Sequelae of Early Childhood Institutionalization in Eastern European Adoptees: The Effects of Early Adversity on Neurobehavioral Development, C. A. Nelson. London, Lawrence Erlbaum Associates. 31: 113-162, 2000.
[132] Lessons Learned Nkundabana: A Model for Community-Based Care for Orphans and Vulnerable Children, Rwanda, CARE, 2005.

and other mental health conditions later in their lives.[133] Child development specialists have documented that birth to eight years are the most critical foundational stages of growth and development. These earliest experiences form the backbone of children's ensuing learning and sets the stage for their ability to cope with challenges later in life. Studies conducted on the impact of ECD and education programs found a direct positive correlation between ECD interventions and early learning school readiness, retention and success in primary school.[134] Family members also report that children enrolled in ECD programs have better social skills, cry less often, and are more responsible in the home.[135] Through targeted studies it has also been found that younger children benefit the most from ECD interventions, with those between the ages of 0 and 36 months representing a highly critical window of development opportunities and vulnerabilities.[136] Evidence-based research from the World Bank has found that access to ECD centers and services plays a significant role in women's economic empowerment and girls' education.[137] Accounts of girls dropping out of school to care for the sick and vulnerable are numerous throughout SSA. The existence of ECD centers enables older caregiver sisters to attend school on a more regular basis. The World Bank research also found that the presence of ECD helps increase and stabilize household financial earnings. Mothers who can access affordable schools and community care facilities for all their children experience a rise in earnings while members of the community care for their children.[138]

As was recently highlighted in the 2007 *Education For All Global Monitoring Report*, disadvantaged children benefit the most from ECD because interventions actually *"compensate for young children's negative experiences as a result of conflict (within family or society) and nutritional or emotional deprivation."*[139] Data from a 2008 draft JLICA report on implementation gaps in services for children affected by HIV/AIDS indicates that the link between education and health—both child survival and development—has been well established. [140] In societies with a high burden of HIV/AIDS children are more likely to be exposed to factors that can detrimentally impact their cognitive development and future psychosocial and physical health. Such factors can include chronic poverty; compromised care-giving behaviors due to parental illness

[133] Segendo, J, and Nambi, J., The Psychological Effect of Orphanhood: A Study of Orphans in Rakai District, Health Transition Review, 7:105-124, 2002.
[134] EFA, Education for All, Global Monitoring Report: Strong Foundations, Early Childhood Care and Education, Paris, UNESCO, 2007.
[135] Cox, A., Horri, T., Granby, B., and Morgan, B., The Importance of Early Childhood Development: Assessing the Quality of Care in Uganda, Master in International Development Capstone Project, GWU and CARE/HACI, 2006.
[136] Zeanah, C., et al, 2005.
[137] Lokshin, M., Glinskaya, E., Garcia, M., The Effect of Early Childhood Development Programs on Women's Laborforce Participation and Older Children's Schooling in Kenya, World Bank Document, 2000.
[138] Ibid.
[139] Education for All Global Monitoring Report: Strong Foundations, Early Childhood Care and Education. Paris, UNESCO, p. 109, 2007.
[140] Palfrey, J. S., Hauser-Cram, P., Bronson, M. B., Warfield, M. E., Sirin, S., & Chan, E., The Brookline Early Education Project: A 25-year Follow-up Study of a Family-Centered Early Health and Development Intervention. *Pediatrics, 116*(1), 144-152, 2005; Shonkoff, J. P., & Phillips, D. A., *From Neurons to Neighborhoods: The Science of Child Development.* Washington, D.C.: National Academy Press, 2000.

or death; and domestic violence that may lead to a constant level of elevated stress hormones in children. Such stress is known to disrupt brain chemistry and lead to impaired learning, memory, social development, and susceptibility to physical illnesses as an adult.[141] It has also been found that early childhood interventions can contribute to improved health and socioeconomic outcomes in adulthood, especially for children in resource-poor settings.[142] Some long-term benefits of experimental ECD programs include improved school achievement, a reduced risk of emotional and behavioral problems, fewer high-risk behaviors, and positive economic outcomes.[143]

Governments, donors and other international stakeholders have for years stated—and most research confirms—that children in need fare better emotionally when they remain living with their families and communities compared to when they live within institutionalized care settings, such as orphanages and state foster care. As data from other JLICA reports illustrate a stable home environment is an important factor in the healthy psychological development of children and that family instability may often result in a variety of negative outcomes. [144] Evidence demonstrates that children are better able to cope with their vulnerabilities when their adult caregiver is healthy and able to provide love and cognitive stimulation.[145] Emotional attachment difficulties in institutionalized children have been consistently observed and reported throughout the world.[146] These difficulties have been linked to the 'indiscriminate friendliness' of institutionalized children toward all adults, irrespective of their familiarity or the care provided.[147] This behavior persists long after children leave the orphanage and is associated with other behavioral problems, particularly attention difficulties.[148] The critical potential links of these institutionalized behavior tendencies and the risks of HIV exposure have not yet been systematically studied in the context of the epidemic in SSA.

[141] Center on the Developing Child at Harvard University, A Science-Based Framework for Early Childhood Policy: Using Evidence to Improve Outcomes in Learning, Behavior, and Health for Vulnerable Children, 2007.
[142] Hawkins, J. D., Kosterman, R., Catalano, R. F., Hill, K. G., & Abbott, R. D., Promoting Positive Adult Functioning Through Social Development Intervention in Childhood: Long-term Effects from the Seattle Social Development Project (Vol. 159, pp. 25-31), 2005.
[143] Ibid; Reynolds, A. J., & Temple, J. A., Extended Early Childhood Intervention and School Achievement: Age Thirteen Findings from the Chicago Longitudinal Study. *Child Development, 69*(1), 231-246, 1998; Schweinhart, L. J., Montie, J., Xiang, Z., Barnett, W. S., Belfield, C. R., & Nores, M., *Lifetime Effects: The High/Scope Perry Preschool Study Through Age 40*, (Monographs of the High/Scope Educational Research Foundation, 14). Ypsilanti, MI: High/Scope Press, 1993.
[144] Adam, E.E., Beyond Quality: Parental and Residential Stability and Children's Adjustment, Current Directions in Psychological Science, 13 (5), 210-213, 2004.
[145] Richter, L., Foster, G., Sherr, L., Where the Heart Is: Meeting the Psychosocial Needs of Young Children in the Context of HIV/AIDS, The Hague, The Netherlands: Bernard van Leer, 2006.
[146] Vorria, P., Papaligoura, Z., Sarafidou, J., Kopakaki, M., et al, The Development of Adopted Children After Institutionalied Care: A Follow-UP Study, Journal of Psychology and Psychiatry, 47 (12), 1246-1253, 2006.
[147] Tizard, B., & Hodges, J. The Effect of Early Institutional Rearing on the Development of Eight-Year Old Children, Journal of Child Psychology and Psychiatry, 19)2), 99-118, 1978.
[148] MacLean K., *The Impact of Institutionalized Care on Child Development*, Development and Psychopathology, 15, 853-884, 2003.

Despite civic and national governmental preference to anchor children in need in family and community-centered care mechanisms considerable foreign funding is still being funneled toward building and managing orphanages rather than for expanding community-based ECD and other child resource projects. For example, the 2004 UNAIDS *Financing the Expanded Response to AIDS* report stated that by 2007 US$1 billion was needed annually for AIDS orphanages worldwide.[149] At the same time, community orphan-care networks were only slated to receive $722 million.[150] This differentiation in funding practices overlooks the evidence from child development literature in general and from outcomes of institutionalized versus community-foster care in Africa that repeatedly point to the benefits of non-institutionalized care for children.[151]

There is a wide scope of literature detailing the poor child development outcomes of institutionalized children.[152] The psychological effects of institutionalization are more permanent than the physical effects[153] and may be more important in predicting later development than malnutrition.[154] Psychological, social and emotional deprivation may be the most important and universal problem of institutional care. The quality of children's relationships with others, particularly an adult caregiver, is an important factor in healthy psychological development.[155] Even in those orphanages with caring staff, the child-adult ratio is necessarily lower and staff rotation patterns and turnover rates often reduce caregiver capacity.[156] Children housed in same-age groups also lack the benefits that the presence of older peers are known to provide.[157] Additional research shows that the higher the rating of psychological deprivation experienced by children in orphanages, the lower the IQ scores are independent of malnutrition status.[158]

[149] UNAIDS, *Financing the Expanded Response to AIDS,* in partnership with the International Labor Organization, Futures Group, UNDP, UNFPA, the World Bank, July 2004.
[150] Ibid
[151] Sherr, Lorraine, Strengthening Families Through HIV/AIDS Prevention, Treatment, Care and Support: A Review of Literature, Joint Learning Initiative on Children and HIV/AIDS, 2008, p. 41
[152] Smyke, A.T., Koga, S.F., Johnson, D.E., et al, *The Caregiving Context in Institution-Reared and Family-Reared Infants and Toddlers in Romania,* Journal of Child Psychology and Psychiatry, 48(2), 210-218, 2007
[153] Wilson, S.L., Post-institutionalization: The Effects of Early Deprivation on Development of Romanian Adoptees, Child and Adolescent Social Work Journal, 20 (6), 473-483, 2003.
[154] Rutter, M. & the ERA Study Team, Developmental Catch-Up, and Defecit, Following Adoption After Sever Global Early Privation, Journal of Child Psychology and Psychiatry, 39 (4), 465-476, 1998.
[155] Vygotsky, L.S., *Mind and Society: The Development of Higher Mental Processes*, Cambridge, MA: Harvard University Press, 1978.
[156] Camras, L.A., Perlman, S.B., Wismer Fries, A.B. & Pollack, S.C., *Post-institutionalized Chinese and Eastern European children: Heterogeneity in the Development of Emotion Understanding*, International Journal of Behavioral Development, 30 (3), 193-199, 2006.
[157] Vygotsky, L.S., *Mind and Society: The Development of Higher Mental Processes*, Cambridge, MA: Harvard University Press, 1978.
[158] Castle, J., Groothues, C., Bredenkamp, D., Beckett, C., O'Connor, T., & Rutter, M., *Effects of Qualities of Early Institutional Care on Cognitive Attainment*, E.R.A. Study Team, English and Romanian Adoptees. American Journal of Orthopsychiatry, 69 (4), 424-37, 1999.

From a physiological perspective, research shows that institutionalized children lose one month of linear growth for every three months spent in institutionalized care[159] and older studies from Africa show increased morbidity and mortality. Cognitive and language deficits have consistently been reported in institutionalized children. [160] Some authors argue that in Africa, given the poverty and chronic food insecurity plaguing many households, institutions may in fact be beneficial for children's nutritional and physical development.[161] Yet another strategy would be to address the poverty of the overall community rather than focus on the relative benefits of a single institution.[162] A JLICA literature review of global research on orphan and non-orphan malnutrition status found conflicting nutritional results.[163] Some studies found no significant differences between vulnerable children housed in family and community foster care and those who live in orphanages, or between orphans and biological children housed in the same family. Other research suggests that the pervasive nature of poverty coupled with high AIDS-death rates has created poor nutrition and health in a majority of children in certain regions in Africa. For example, a study in Uganda found that despite the nation's adequate food supply, stunting rates were 54 per cent and rising quickly, with no difference between orphans and non-orphans. The effect was worst in Western Uganda where the AIDS crisis is most acute.[164] Still other evidence points toward poorer health and nutritional outcomes for orphans and other children in need in general. A large cross-sectional study of more 30,000 children in Zimbabwe found that HIV/AIDS-affected orphans and other children were more likely than non-orphans to have recently had diarrhea or an acute respiratory infection, and were more likely to be stunted or underweight.[165]

An analysis of UNICEF surveys that collected nutritional status data from institutionalized children found that children in orphanages in Malawi and Jamaica were actually nutritionally worse off than those living in poor households. [166] The survey found no significant difference between the nutrition of fostered orphaned children and non-orphans, indicating that community foster care was adequate and did not differentiate or negatively affect orphaned children. Similarly, studies have found no difference between fostered orphans and non-orphans in health status and care, school attendance,

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[159] MacLean, K., *The Impact of Instutionalization on Child Development,* Development and Psychopathology, 15, 853-884, 2003.
[160] Smyke, A.T., Koga, S.F., Hohnson, D.E., Hox, N.A., Marshal, P.J., Nelson, C.A., Zeanah, C.H. & the BEIP Core Group, The Caregiving Context in Institution-reared and Family-Reared Infants and Toddlers in Romania, Journal of Child Psychology and Psychiatry, 48 (2), 210-218, 2007.
[161] Panpanich, R., Brabin, B., Gonni, A. & Graham, S., Are Orphans at Increased Risk of Malnutrition in Malawi? Annals of Tropical Pediatrics: International Child Health, 19)3), 279-285, 1999
[162] Sherr, Lorraine, Strengthening Families Through HIV/AIDS Prevention, Treatment, Care and Support: A Review of Literature, Joint Learning Initiative on Children and HIV/AIDS, 2008, p. 42.
[163] Ibid.
[164] Bridge, A., et al, Nutritional Status of Young Children in AIDS-affected Households and Controls in Uganda, American Journal of Tropical Medicine, 74 (5), 926-931, 2006.
[165] Watts, H., et al, Poorer Health and Nutrition Outcomes in OV Young Children Not Explained by Greater Exposure to Extreme Poverty in Zimbabwe, Tropical Medicine and International Health, 12 (5), 584-593, 2007.
[166] Rivers, J., Silvestre, E., & Mason, J., Nutritional and Food Security Status of Orphans and Vulnerable Children: Report of a Research Project Supported by UNICEF, IFPRI, and WFP, 2004.

lodging and sanitation facilities and clothing.[167] Some authors suggest that fostered children may be stigmatized and unfairly treated in favor of biological children but while this may be the case in isolated households, current evidence does not support this conviction.[168] Foster care in a family environment is likely to offer many benefits that institutionalized care cannot, particularly for children's psychosocial development.

Evidence-based research points overwhelmingly to the benefits of caring for children in need within family and community settings. A number of community-based interventions—including three of the four programs featured in this report—have proven successful in providing physical, psychosocial, nutritional and economic support to HIV-affected households, foster families and communities that care for children in need. These holistic interventions are designed to keep all family members healthy, ultimately improving children's emotional, nutritional and overall health stability. Though more research needs to be conducted, existing research appears to indicate that family and community-centered approaches are both sustainable and economical, and given current evidence in determinants of healthy psychosocial development, should be the primary focus of efforts to care for children in need.[169]

Funding for ECD in HIV/AIDS Programs

Research conducted in 2005 by the Bernard van Leer Foundation that tracked funding for ECD programs revealed that two prominent categories of early childhood intervention currently attract the most significant funding—PMTCT and the care of orphans and vulnerable children. PMTCT programs are generally well established and usually involve a one-off medical intervention and subsequent promotion of changes in breastfeeding behavior. Under the category of "OVC" there is potential to reach the youngest (0–8) age group, but it is largely unrealized and care for this age group is lacking significant resources. Before more resources can be routed in the direction of ECD-HIV/AIDS interventions, more research needs to be conducted that examines the specific interactions between ECD on children and families affected by HIV/AIDS.[170] According to the study, most ECD and HIV/AIDS work carried out in Africa today falls under the auspices of small NGOs and several larger organizations, such as the Bernard van Leer Foundation and the Consultative Group on Early Childhood Development. As of 2005 UNICEF and UNESCO began concentrating greater efforts to bridge the funding and programming gaps in the ECD service area. A rough estimate from UNESCO suggests that less than

[167] Lindblade, K.A., Odhiambo, F., Rosen, D.H. & DeCock, K.M., Health and Nutritional Status of Orphans Six Years Old Care for By Relatives in Western Kenya, Tropical Medicine and International Health, 8 (1), 67-72, 2003.
[168] Masmas, T.N., Jensen, H., daSilva, D., Hoj, L., Sandstrom, A., Aaby, P., The Social Situation of Motherless Children in Rural and Urban Areas of Guinea-Bissau, Social Science and Medicine, 59, 1232-1239, 2004a.
[169] Sherr, Lorraine, Strengthening Famili
es Through HIV/AIDS Prevention, Treatment, Care and Support: A Review of Literature, Joint Learning Initiative on Children and HIV/AIDS, 2008pg. 45.
[170] Dunn, A,, The Way the Money Goes: An Investigation of Flows of Funding and Resources for Children Affected by HIV/AIDS, Working Papers in Early Childhood Development, Young Children and HIV/AIDS sub-Series, Bernard Van Leer Foundation, 2005, p. vi.

five per scent of HIV/AIDS money is earmarked towards very young children.[171] Very little PEPFAR money appears to specifically target very young children although some orphans and other vulnerable children in need likely benefit from grants made to Habitat to Humanity, Opportunity International and Catholic Relief Services.[172] In order to direct more money to this area it is important to examine the funding mechanisms currently distributing HIV/AIDS funds. Funding decisions are often based on political factors rather than front-line responses informed by those most directly affected by the pandemic. This lack of informed direction and the fact that attempts to address HIV/AIDS are falling far short of urgent and effective responses support arguments for deeper exploration and shifts in the current funding paradigms.

Some prominent ECD advocates:

UNESCO: Builds partnerships for documenting issues and initiatives affecting young children and promotes information sharing and debate by way of email forums and website features.[173]

UNICEF: A prominent ECD advocate, UNICEF publishes reports on HIV/AIDS-ECD and convenes important working groups and conferences on the topic.[174]

Working Group on Early Childhood Development: Provides strategic support and assistant to African governments committed to investing in ECD. Founded in 1997 with UNICEF as its lead agency, it works closely with the Association for the Development of Education in Africa.[175]

Consultative Group on Early Childhood Care and Development: An international inter-agency group dedicated to improving the condition of young children at risk. [176]

Early Childhood Development Network for Africa: Created in 1994, the network develops information and communication strategies, documentation, case studies, and training and action research programs. It also contributes to integrated ECD policies and programs. One of its more recent activities is the "Young Child and HIV/AIDS" initiative to help meet the needs of orphans and other vulnerable children in need in Africa.

Bernard van Leer Foundation: A long-time ECD proponent the foundation works to expand public knowledge and action on ECD and HIV/AIDS. It assesses program

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[171] Ibid, p. 29.
[172] Ibid.
[173] UNESCO HIV/AIDS website <http://portal.unesco.org/en/ev.phpURL_ID=1134&URL_DO=DO_TOPIC&URL_ SECTION=201.html>
[174] UNICEF United Nations Children's Fun <www.unicef.org>
[175] The Working Group on Early Childhood Development – Dutch Ministry of Foreign Affairs. Contact <jeannette.vogelar@minbuza.nl> and see www.adeanet.org/workgroups/en_wgecd.html
[176] The Consultative Group on Early Childhood Care and Development (CGECCD) Contact Kathy Bartlett or Louise Zimanyi at <info@ecdgroup.com> and see <www.ecdgroup.com>

response to specific pandemic challenges and brings ECD concerns to the forefront of national government and international donor response.[177]

World Bank Early Childhood Development Team: A collaborative effort of the Bank, the Consultative Group on Early Childhood Care and Development and the Organization of American States providing links and information-sharing.[178] Since 1990 the Bank has increased its investment in ECD programs from approximately US$ 126 million to a total of about US$ 1.6 billion in 2006.[179] While some of these Bank financed projects are freestanding, the majority are linked to human development projects with an ECD component.[180]

Costs and Cost-Effectiveness

Though no specific budgetary numbers for the 5x5 Model were available for review within the context of this report, The World Bank's website section on ECD offers a global research overview about who pays for ECD services, including innovative strategies for making ECD available in poor communities where children are most in need.[181] The Bank states that expenses for ECD programs can be divided into several cost components that should be taken into account when planning for project implementation and budgetary concerns. These components can be distinguished in investment and operating costs. Findings show that while investment costs are often financed by outside funding, operating costs are often covered by other sources over time, such as the government, the community, parents or the private sector.

Government: The most common source of financing for early childhood programs according to the Bank research is from government budgets. ECD programming is often paid for from funds from the Health, Education or Social Services budgets. At times funds will be assigned through budgets for women's development, rural development, agriculture, or employment. Sometimes, governments earmark funds for ECD programs through special payroll or other taxes, or through trust funds rather than through regular budget. The trend among international financial institutions to require national governments to decentralize social services has shifted responsibility for financing ECD programs down to sub-national or local levels. Many national governments share the cost of early childhood interventions with sub-national governments and program beneficiaries. Kenya's central government, for instance, funds the training of caregivers, while local authorities provide and maintain preschool program sites. India's national

[177] Bernard Van Leer Foundation (2002a) Annual Report <www.bernardvanleer.org>
[178] World Bank Early Childhood Development Website <www.worldbank.org/children/>
[179] The World Bank Website, Early Childhood Development, theworldbank.org, 2006.
[180] The World Bank Website, Early Childhood Development, worldbank.org
[181] Wilson, Sandra, *ECD Programs: Lessons from Developing Countries*, The World Bank, Human Development Department, Washington, DC, 1995; Evans, Judith L. with Robert G. Myers and Ellen M. Ilfeld, *Early Childhood Counts: A Programming Guide on Early Childhood Care for Development*, The World Bank, Washington, D.C., 2000; Myers, Robert, *The Twelve Who Survive: Strengthening Programs of Early Childhood Development in the Third World*, 2d ed. (Ypsilanti, MI: High/Scope Press), 1995; Barnett, W. Steven. *Costs and Financing of Early Child Development Programs*, In: M.E. Young (editor), Early Child Development: Investing in our Children's Future. Amsterdam: Elsevier Science B.V. 1997.

government pays for everything but supplementary feeding, which is financed by the states.[182] Many developing countries heavily subsidize childcare services to ensure that they are available to poor families, who are known to spend a majority of their income on food, housing, and transportation. The government of Columbia, for example, finances 85 per cent of the costs of its Hogares Comunitarios de Bienestar program primarily through a payroll tax. In Mauritius the government created the Export Processing Zone (EPZ) Welfare Fund as a concession to EPZ workers who make up 20 per cent of the country's labor force but do not benefit from the more advantageous labor regulations that apply outside the zones. Created to finance social services for EPZ workers and their children, the fund derives its revenues from a tripartite system of monthly payments from the state, employees, and employers. The EPZ social service fund provides start-up and operating grants to non-governmental organizations to create and run day care centers. It also subsidizes preschool fees for the children of EPZ workers. Under this tripartite funding system, the national government contributes about 10 per cent of EPZ social service fund revenues.

Families: Most countries employing ECD interventions have instituted user fees to finance at least part of their early childhood programs. In Latin America, parents participating in Colombia's Community Child Care and Nutrition Project, for instance, are expected to contribute on a sliding scale according to family income. In Bolivia's Integrated Child Development Project parents pay a flat monthly fee for the first child and a decreasing fee for each additional child enrolled. Parents often pay for the costs of caregivers' salaries or honorariums. Families and communities can also make contributions in-kind, such as construction and rehabilitation activities, voluntary work, food preparation, etc. Cost recovery strategies that aim to cover most or all of the costs through user fees have several drawbacks, especially for the poorest families that depend on ECD services the most.

Community: Social organizations such as community, charitable, religious and other non-governmental organizations can play an important role in financing ECD programs. They might provide the entire cost of services or pay part of the costs, either through money or in-kind contributions such as time and labor, donation of materials or the location for a childcare center.

Private Sector: The role of the private sector in financing ECD services varies. Some childcare centers are run as private, for-profit businesses that often target wealthier children in order to receive the required fees to cover costs, or receive subsidies from the government to enable lower-income children to access services. Private sector contributions might also consist of an employer financing a daycare center at or close to the workplace. International organizations may also contribute relatively large amounts of money at the early stages of an ECD project. This money is generally used to establish the program, roll out pilot or small-scale projects, and lay the foundation for implementation on a larger scale. This type of funding often covers part of the initial

[182] Myers, Robert, *The Twelve Who Survive: Strengthening Programs of Early Childhood Development in the Third World*, 2nd Edition, Ypsilanti, MI: High/Scope Press, 1995.

investment costs while funding for operating costs usually decreases over time. In many cases, international organizations expect ECD projects to become sustainable and rely on national and local rather than external support.

Funding ECD Programs By Granting Micro-Enterprise Loans to Women: A relatively new alternative for financing ECD programs is the creation of micro-enterprise projects enabling women to earn income by establishing home-based day care centers in their homes. Start-up loans are often accompanied by training and technical support to ensure thorough understanding of the value of early childhood interventions and quality service delivery. ECD-linked micro-finance strategies may also be used to finance separate income-generation projects, such as a garden attached to the preschool or the production and sale of handicrafts made by women who enroll their children in the child center during working hours. Once produce or crafts have been sold, a per centage of profits may be allocated to support the operation of the daycare center. Other women may obtain loans from micro-enterprise projects to earn income and pay directly for childcare services themselves. In Vietnam, for example, such a program was established through Home-Based Day Care Centers in conjunction with a Rotating Savings and Credits Association for Women. In Thailand ECD proponents the Christian Children's Fund have developed a financing scheme in which loans paid back to village loan funds are funneled into a capital fund to support ECD programs in the community on a continuing basis. Similarly, in Kenya, Tanzania and Uganda the Madrasa preschool program is experimenting with the creation of an endowment that would provide funds on a more continuing basis. The endowments consist of funds raised by the community and the Madrasa program. The annual income generated by the endowment would supplement the participating schools' finances and lead to more regular payment of teachers' salaries.

Challenges to Scale Up and Lessons Learned

Despite the challenges of rolling out ECD programs in resource-poor settings, there are numerous cases showing the feasibility and success of integrated family-centered programs like the 5x5 Model. Such success stories combine nutrition, school readiness and improved family and community caregiving under the rubric of primary health care delivery.[183] As highlighted in the JLICA report on gaps in services, accessibility, uptake and adherence to the specifications of an ECD program may be severely impacted by the impoverished conditions of a population plagued by transportation barriers, malnutrition and fatigue from illness, such as HIV/AIDS, malaria and TB. Additional barriers to effective and sustainable ECD scale up include lack of awareness among mothers, health care providers, and communities about the need to support early childhood development. The absence of legislative and financial support from governments and vulnerable mothers and children's difficulty accessing services also impede scale up.

[183] Engle, P. L., Black, M. M., Behrman, J. R., Cabral de Mello, M., Gertler, P. J., Kapiriri, L., et al., Strategies to avoid the loss of developmental potential in more than 200 million children in the developing world. *Lancet, 369* (9557), 229-242, 2007.

Program Case Study 3: CARE's Case Manager Model: Linking Community and Facility-based Health Services to PLWHAs and their Families

Of an estimated 190,000 HIV-infected Rwandans 100,000 are women and 27,000 are children, according to UNAIDS.[184] By 2010 the per centage of orphans is expected to grow from 13 per cent to 20 per cent—with 83 per cent of these cases due to AIDS.[185] The first ARV site was introduced in Rwanda in 1999—five years after the genocide that claimed more than 800,000 lives and significantly escalated HIV-infection rates, particularly among women. Since that time treatment availability has expanded to more than 100 sites.[186] As stated earlier, throughout the developing world it is not uncommon for patients enrolled on ART to experience interruptions in their drug therapies due to lack of medicinal supplies, drug side effects or lack of proper nutrition follow-up.[187] Research among 233 ART patients in Kigali, Rwanda found that over half had experienced at least one treatment interruption. Reasons for lack of adherence included drug shortages, drug intolerance, domestic violence, financial inaccessibility and doubts about treatment efficacy.[188]

In addition to tackling adherence challenges, Rwandan health providers are faced with the task of strengthening linked referral systems in rural communities. The absence of these important local networks often leaves HIV-affected families isolated and hinders their ability to access the full range of health, psychosocial and economic services available to them locally. Research from the U.S. that surveyed 642 HIV-positive individuals found that case managers (CM) could be a successful mechanism for integrating formal care services into informal delivery systems. Study participants paired with a CM were more likely to utilize community-based services than participants without a CM.[189] Other research conducted in 2001 found that individuals assigned to a CM experienced a decrease in unmet needs for income assistance, health insurance, home health care and emotional counseling follow-up.[190]

[184] UNAIDS, *AIDS Epidemic Update*, December 2005.
[185] UNAIDS, UNICEF and USAID, Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action, USAID, 2004.
[186] Kayirangwa, E., et al, Current Trends in Rwanda's HIV/AIDS Epidemic, Sexually Transmitted Infections, 82 (Suppl-1):27-31, 2006.
[187] CARE and Hope for African Children Initiative, *Lesson Learned: Rwanda*, 2008.
[188] Fischer, A., Karasi, J., et al, "Antiviral Efficacy and Resistance in Patients on ART in Kigali, Rwanda: The Real Life Situation in 2002, HIV Medicine, 7:64-66, 2006.
[189] London, A., Leblanc, J., Anshensel, C, The Integration of Informal Care, Case Management and Community-based Services for Persons with HIV/AIDS, AIDS CARE, 10:4, 481-503, 1998.
[190] Katz, M., Cunningham, W., Fleishman, J., Andersen, R., Kellogg, T., Bozzette, S., Shapiro, M., Effect of Case Management on Unmet Needs and Utilization of Medical Care and Medication Among HIV-Infected Persons, Ann Intern Med, 135, 557-565, 2001.

Program Structure

Established in 2004, CARE's CM integrated model addresses the complex and numerous needs of PLWHA and their families with a specific focus on enhancing ART adherence and expanding utilization of linked local referral systems. Though no longer funded by PEPFAR, the program continues to support the Rwandan government's National Strategic Plan in the fight against HIV/AIDS. Specifically, CARE states that the CM program contributes directly to the national plan Axis III to improve care and treatment for PLWHA. It also supports Axis II to mitigate negative socioeconomic conditions among HIV-affected households by linking them to income-generating activities and other economic strengthening opportunities.[191] First implemented in the former provinces of Butare and Cyangugu, in 2005 the program expanded to Gisenyi, Kibuye, Umutara, Gikongoro and Gitarama. Since its inception 149 case managers and 1013 unpaid community volunteers have been recruited, trained and now deliver care in 18 districts.[192] Anecdotal evidence provided by CARE shows that its CM model positively impacted ARV adherence with home visits highlighted as a particularly important factor. Respondents repeatedly cited positive psychosocial program benefits, including increased social support and a heightened sense of hope concerning their future. The program was also credited with reducing stigma and discrimination within the household as well as encouraging PLWHA to seek out services and support without being ashamed of their status.[193]

Like AMPATH and PIH, CARE adheres to the belief that access to HIV/AIDS prevention, care and treatment services are fundamental human rights, and that protecting these rights not only lead to fewer new HIV-infections but also helps affected families cope more easily with the effects of the illness. Since 1987 CARE has sponsored more than 150 HIV prevention projects in 40 countries and has worked to mitigate the impact of the pandemic on economic development and community well-being. Central to its work are efforts to increase affected families' access to integrated high quality care and linked support services. CARE's HIV/AIDS projects strive to be community-based, comprehensive and multi-sectoral, and often address the particular vulnerabilities of women and girls.[194] CARE strives to integrate a continuum of care services, including food and nutritional supports to children and families affected by HIV/AIDS, particularly ART patients.[195]

Case Managers

[191] Thurman, T., et al, CARE Rwanda's Case Management Model: Evaluation Report, July 17, 2006, National University of Rwanda, School of Public Health, 2006, p. 13.
[192] Lesson Learned: Rwanda, CARE and Hope for African Children Initiative, 2008, p. 4.
[193] Thurman, T., et al, CARE Rwanda's Case Management Model: Evaluation Report, July 17, 2006, National University of Rwanda, School of Public Health, 2006, p. 7.
[194] The Future of PEPFAR: Comprehensive Approaches, Sustainable Results, CARE, 2008, p. 2.
[195] Ibid, p. 4.

Though the value of the CM model has been documented extensively in developed nations CARE found few citations in support of such an approach being implemented in resource poor settings. CARE's CMs fulfill a similar role as CHWs in that they provide a bridge between families and health care facilities—Formation Sanitaire (FOSA), help ensure patient ART adherence and train and supervise home-based care volunteers. CARE describes its CMs as nurses (82 per cent) and social workers (18 per cent) based in and employed by FOSAs receiving financial support from CARE. Those with nursing backgrounds are able to respond to and assist with FOSA health care operations in addition to their CM duties, while those with social work background may often be better equipped to respond to the needs of unpaid community and local referral partners.[196] An external program evaluation found that FOSA managers reported a high degree of satisfaction with nurse CMs precisely because they could also fulfill health care staff functions in the clinic and family setting. Clients also reported that nurses were helpful in resolving minor health issues during their home visits. Still, nurse CMs risk being overwhelmed by tasks unrelated to their specific CM duties.[197] Case managers carry an average caseload of 63 clients and conduct approximately 6.3 home visits with each patient per month. After assessing the health, psychosocial condition and economic situation of their clients and their families, the CMs develop individualized plans to link them to additional health care, legal assistance, nutrition and food support, housing and shelter assistance, psychosocial services, and financial or in-kind support for transportation, school fees and clothing.

Unpaid Care Workers

CARE's CM program relies on unpaid care workers—referred to as "volunteers"—to perform home visits, provide care, assess household needs and solicit the help of case managers when they encounter problems beyond their expertise. Unpaid workers' workload includes ARV adherence and monitoring, family conflict resolution, counseling, and other types of assistance. Ninety-two per cent of CMs said they felt they were indispensable to the CM program. Local referral partners also cited how important volunteers were in informing them of sick or highly isolated individuals in need of intervention. Health providers commented that they rely on volunteers to be messengers communicating health information and recommendations to patients. Investing heavily in training community volunteers and placing them under the supervision of health facility-based CMs has tremendously improved the volunteers' integration into the health system and the quality of home-based care delivered to patients.[198] Volunteers are particularly well received by patients when they are also HIV-positive and are members of local PLWHA associations. CARE continuously seeks ways to ensure the meaningful participation of PLWHAs as outlined in the GIPA Principles—Greater Involvement of People with HIV/AIDS. Derived from the Paris AIDS Summit Declaration in1994, the GIPA Principle is a philosophy seeking to engage HIV-positive people at every level of

[196] Thurman, T., Haas, L., Dushimimana, A., *CARE Rwanda's Case Management Program: Evaluation Report*, July 17, 2006, pg. 6.
[197] Lessons Learend: Rwanda, CARE and Hope for African Children Initiative, 2008.
[198] Ibid.

the response to the HIV/AIDS pandemic. CARE states that it has found that PLWHAs are more committed and motivated to work as volunteers in HIV programs than already over-burdened paid community health workers.

Referrals and Links

In 2006 the National University of Rwanda School of Public Health with technical support from the Tulane University School of Public Health in Louisiana conducted an external evaluation of the CM Model. A mixed research methodology was employed, emphasizing qualitative methods to better capture the attitudes and perceptions of key stakeholders. The survey found that health providers acknowledged an improvement in the general health of clients as a result of psychological and other types of support provided by CMs. The successful integration of CMs into FOSA operations had successfully filled a gap in client support services and trained-health personnel that had not adequately been addressed prior to the CARE pilot. For example, facilities staffed with CMs introduced testing for malnourished children, pregnant women and other at-risk individuals, and reached out to and educated child headed households about the value of voluntary testing and counseling (VTC). When CARE's financial support for CM salaries came to a close in June 2006, nearly 60 per cent of FOSAs continued to use their own limited resources to retain their services. This is perhaps the most convincing indicator of the model's cost-effectiveness, says CARE. CMs were initially regarded as external members of the FOSA team but over time they were gradually streamlined into all staffing and program operations, with nurse CMs taking on additional health duties at the clinic and in patient's homes. CMs began to participate regularly in staff meetings and were subjected to the same rules and regulations as other FOSA employees. More than 80 per cent of FOSA staff considered the CM Model as one of its own programs rather than as an external program. One FOSA manager in the former Kibuye Province reported that prior to the start of the case management program, daily visits to the center by PLWHA in the catchment area were completely overwhelming the clinic staff capacity. By the end of the project period, the establishment of the community-based care and support system had greatly reduced direct patient visits to the health center, while at the same time improving the quality of local care available to PLWHA and their families. The manager reported that the cost of maintaining the CM on her staff today was more than offset by the savings from the reduction of visits by PLWHAs, many of whom require free care. [199] As one health provider said: *"Before this program [FOSA] was not capable of doing the following: taking care of nutritional needs of bedridden PLWHAs, taking care of the medical needs of PLWHAs and working with the PLHWA associations. Actually, all of this is possible now thanks to this program."*[200]

Despite CM efforts to increase PLWHA linkages to resources and services via referral networks, demand still outweighs supply. CMs rely on a short list of referral partners and CARE has previously documented the difficulties encountered when attempting to establish expanded referral lists, either from headquarters or from the provincial

[199] Ibid, p. 7
[200] Thurman, T., et al, CARE Rwanda's Case Management Model: Evaluation Report, July 17, 2006, National University of Rwanda, School of Public Health, 2006, p. 26.

government level.[201] Referral agencies include mostly small scale community associations and groups offering services ranging from legal and administrative support to assistance in joining community health insurance programs, income generating activities, school feels and food distribution. Though each CM often has access to only a small number of referral partners, this small ratio may facilitate regular communication and positive relationships. Referral partners also expressed appreciation for the program and felt it accentuated and strengthened their work in the community. Community leaders play a critical role in mobilizing local service providers, particularly for socioeconomic assistance and in educating community members about the role of CMs and volunteers.[202]

CM Responsibilities

Case managers are responsible for a range of activities that ensure family-centered health care delivery. Working closely with district hospitals or health centers, CMs identify clients through FOSA-based VCT/PMTCT/ARV programs, PLWHAs associations and community volunteers. CMs also:

- Identify client's needs and link them with appropriate service providers.
- Coordinate, monitor, evaluate and advocate for a package of multiple services on behalf of their clients.
- Facilitate access and adherence to ARV treatment and link PLWHAs and the children in need under their care with community-based care and support services.
- Train and supervise community volunteers who provide home-based care to clients, including adherence to ARV and monitoring the possible side effects of the drugs.
- Strengthen and develop institutional and organizational capacity to care for PLWHAs and children in need through advocacy efforts and establish effective linkages for HIV detection, treatment and support.
- Assess the client and his/her family's needs as well as their socio-economic situation and support network.
- Design, implement and evaluate personalized client plans to access services and treatment.

Client Profile

Most of the HIV-positive clients served by the CM Model have a significant caregiving burden themselves, with nearly one half (47 per cent) reporting having three or more children living in their household. An additional 29 per cent reported that a second HIV-positive person was also living in the household. Clients stated concerns about meeting the needs of their children, with a majority experiencing difficulty providing children's educational, nutritional and health service needs. Overall, 94 per cent reported a lack of sufficient earnings to cover everyday needs. Thirty-four per cent reported being members of a credit savings and loans group and 70 per cent indicated having health

[201] Bedoya-Hanson, S, Field Report: Case Management Program, Experiences From the Field," January 18, 2006.
[202] Lessons Learned: Rwanda, CARE and Hope for African Children Initiative, April 2008.

insurance.[203] Clients range in age from 6 to 65, with a mean average age of 37. Approximately 88 per cent of clients rely on farming as their primary income source. Half (45 per cent) have never attended school and 36 per cent indicated an inability to read, write and count. The majority are single and a large number, 38 per cent, are widows. Client poverty was identified as a primary need among HIV-affected families and the need for food was continually highlighted. More than 75 per cent of referrals made by CMs on behalf of their clients regarded food and nutritional support.[204] Other research conducted in 1994 in Rwanda found that the reported services most needed among 47 HIV-positive women in Kigali included housing, employment and money. Women also expressed concern about meeting their families' needs for food and childcare in the event they became ill.[205]

CARE Pay Policy and Volunteer Turnover

While CARE compensates its CMs it does not have enough available program funds to pay the vast network of more than 1,000 community volunteers who actually deliver services to patients and their families on a daily basis. According to CARE staff, this is lack of payment is also due in large part to an overall program philosophy that seeks to ensure community self sufficiency and resiliency, regardless of external funds and program staff.[206]

This marked difference in hiring and compensation philosophy is a major point of departure between CARE and the other program highlighted in this report. The continuity and obvious psychological benefits of home-based visits is a pivotal component of sustained ART adherence and family-centered care delivery. AMPATH and PIH have both stated that program care continuum is best protected when all workers are compensated and properly motivated to perform their professional duties. CARE literature, on the other hand, articulates its belief in preparing communities to *"solve the problems they face and own the solutions they seek."* Like the policymakers interviewed about AMPATH who voiced their apprehension for program sustainability once PEPFAR funds are withdrawn, CARE is genuinely concerned with developing a community-owned program architecture that can withstand the withdrawal of foreign funds and technical support. Through its many years of experience, it has found that effective community mobilization leads to solutions that are sustainable regardless of external actors and funding. [207] CARE cites recent studies showing that "AIDS competent" communities are characterized by: intra-community solidarity, a sense of ownership of the problem, safe spaces to talk and share openly, confidence in local strengths, knowledge and skills, and relationships with relevant actors outside the community.[208]

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[203] Thurman, T., Haas, L., Dushimimana, A., *CARE Rwanda's Case Management Program: Evaluation Report*, National University of Rwanda School of Public Health, July 17, 2006, p. 19.
[204] Ibid, Table 6: Reported and Recorded Referrals Made for Clients, pg. 8.
[205] Keogh, P, et al, The Social Impact of HIV Infection on Women in Kigali, Rwanda: A Prospective study, Social Science & Medicine, 38(8), 1047-1053, 1994.
[206] Zoll, Miriam, Phone Interview with CARE Staff, May 2008.
[207] The Future of PEPFAR: Comprehensive Approaches, Sustainable Results, CARE, 2008, p. 2.
[208] Campbell, C., et al, Building Contexts that Support Effective Community Responses to HIV/AIDS: A South African Case Study," American Journal of Community Psychology 39 (2007) 347-363.

Two additional studies of community mobilization on behalf of orphans and other vulnerable children in need found that community ownership was essential for sustained community action.[209] For example, of 30 community-level committees initiated in Malawi and Zambia between 1996 and 2002, the majority remained active and committed to meeting the needs of children in need four years later. The study found that two factors worked against sustainability: first, when external resources were provided before a community group took root and developed its own internal resources; and second, when pressures from donors pushed money to communities too rapidly.[210]

The 2006 program survey evaluation stated that CARE volunteers are motivated primarily from *"the sense of pride in their work, the application of new skills they learn in trainings, and the positive changes they see resulting from their activities."* More than 80 per cent of CMs said they felt that HIV-positive individuals were the most motivated volunteers. The evaluation also cited inadequate resources and incentives among CMs and volunteers—who are often poor and in need of basic support themselves—as a pressing concern. Many respondents noted that volunteers' financial and physical restrictions hindered their effectiveness. *"We don't have means for ourselves so we can't help PLWHA,"* said one volunteer. CMs and volunteers both raised issues about the inadequacy of the human, financial, material and educational resources needed to meet the demands of the job and retain staff/volunteer commitment and satisfaction. Volunteers spoke of the need for material provisions to aid their work and reward them for their efforts. They also mentioned the difficulties they face when they visit clients "empty-handed" and suggested that they would like to bring something, such as flour or sugar.[211]

Quoting from the report:

"The responsibilities of CMs are met with what is considered substandard salaries as well as irregular pay distribution from CARE. Health facility staff felt the salaries of CMs should be increased to a more equitable level with other clinic employees. Although CM salaries were determined utilizing Government of Rwanda matrices for nurses at the appropriately equivalent pay scale, CARE suggests that primes paid by health facilities or donor-supported health facilities aggravate differences in pay received. CARE provides funds for CM salaries directly through the health facilities for distribution… In addition, case managers and volunteer health providers indicated that vacation rights were not honored due a lack of staff coverage to fill their duties…The CM program has been plagued by a high turnover of case managers."[212]

Poverty and the Burden of Care

[209] Donahue, J. and Mwewa, L., Community Action and the Test of Time: Learning from Community Experiences and Perceptions, Washington, DC: USAID, December 2006.
[210] Ibid.
[211] Thurman, T., Haas, L., Dushimimana, A., *CARE Rwanda's Case Management Program: Evaluation Report*, July 17, 2006, pg. 7.
[212] Ibid, pg. 22

These findings, and the poor economic profiles of the client base stated earlier in this section, point once again to the pervasiveness of poverty within patient and caregiver households. Through a survey conducted in Botswana of 1033 working adults, McGill University researchers analyzed the experience of adults caring for orphans and other vulnerable children in need. Over one-third of working adults were caring for orphans and many did so with few financial resources: 82 per cent were living on household incomes below US$10 purchasing power parity adjusted per person per day. Because of their caregiving responsibilities, they were less able to supplement family income with overtime, weekend, evening, or night work. At the same time care responsibilities meant orphan caregivers spent fewer hours caring for their own children and other family members. Nearly half of orphan caregivers had difficulties meeting their own children's needs, and nearly 75 per cent weren't able to meet with their children's teachers. Pay loss at work compounded problems: One-quarter of orphan caregivers reported having to take unpaid leave to meet sick childcare demands and nearly half reported being absent from work due to children's routine health care needs. The research makes clear that if families are to continue providing adequate care for orphans and survive economically, significant increases in social supports—such as direct cash transfers, child welfare grants or old age pensions—and improvements in working conditions must be implemented.[213]

An important study investigating the gendered nature of care delivery and how these responsibilities actually impact the caregiver was published in the *Journal of AIDS Research* in 2006. Research was carried out in two Zulu-speaking semi-rural townships in South Africa known for its high unemployment and low literacy levels. Interviews were conducted with family and community volunteer caregivers who received no remuneration and may or may not have benefited from any formal training.[214] The research found common shared signs and symptoms of socio-economic challenges, as well as emotional and psychological difficulties including tearfulness, nightmares, insomnia, worry, anxiety, fear, despair and despondency.
Women exhibited a disproportionate share of these burdens because they were generally closest to the patients and performed the most emotionally wrenching tasks. They were more likely than men to witness the deaths of these patients and were more likely to experience far-reaching emotional and psychological consequences as a result of their caring responsibilities.

Some family members and volunteers were themselves living with HIV or AIDS while at the same time providing care to others living with the same condition. Caregivers reported that witnessing the debilitating symptoms and pain of the illness on a daily basis was a constant reminder that they or their relatives would experience a similar demise. Caring for patients and observing their deaths was thus a persistent source of psychological trauma: *'You know sometimes the caregivers may have HIV or have siblings or relatives who have similar sickness and symptoms like their patients, and*

[213] Heymann J, Earle A, Rajaraman D, Miller C, Bogen K., Extended family caring for children orphaned by AIDS: balancing essential work and caregiving in a high HIV prevalence nations, AIDS Care, 2007, McGill University.

[214] Akintola, O., Gendered Home-Based Care in South Africa: More Trouble for the Troubled, African Journal of AIDS Research, 5(3): 237-247, pp. 237-247, 2006.

when their patient dies they feel it and say — so this is how I or my sibling or relative is going to die too.' (28-year-old home-based care coordinator).

One volunteer described how a colleague had noticed that she had symptoms of AIDS but had not taken an HIV test; she broke down in tears at their meeting, saying in frustration, *'I am tired of not knowing what is wrong with me.'*

Parents reported experiencing enormous emotional stress while caring for their children or witnessing their death. They also worried about who would take care of their children after they died. One HIV-positive mother struggling to cope with her own deteriorating health became psychologically devastated and depressed when she discovered that her last child was HIV-positive: '*When they told me that I was positive I cried because I felt very sorry for my children [who] I am going to leave. I was also worried and stressed because of my last child, I did not know he had HIV and I also got depressed, and was even admitted to the hospital for two weeks. If I look at other children of the same age they look very healthy and they are taken care of properly and you can see that they are not sick like he is'* (44-year-old HIV-positive family caregiver).

Most of the women in the study were unmarried and their poor economic condition and lack of financial support from men was a key variable that in general presented an overall stressful situation for family members. A 75-year- old female breadwinner who headed a multi- generational household had spent considerable money caring for her daughter and granddaughter: *'It is hurting so much because sometimes I am unable to sleep at night thinking of what to do and not to do. Because all the money I spend and everything I do just disappears. Nothing is going on well.'* Volunteers who served as the primary caregivers in other people's homes said they felt under pressure to provide food and money for patient's transport to health facilities. Thus, caregivers experienced psychological stress while worrying about their own financial situation and that of their patients. [215]

CM Model Program Challenges

The National University of Rwanda-Tulane University evaluation identified a range of program challenges through interviews with clients, CMs, volunteers, community members and health care providers. It is important to note that many of these same challenges were articulated as obstacles to growth in the AMPATH program evaluation cited earlier in this report. This suggests that family and community-centered HIV/AIDS projects in different geographic regions of Africa might still share a similar set of barriers scale up and success.

Compensation to Volunteers/Unpaid Care Workers and Higher Salaries for CMs: As mentioned earlier in this section, both volunteers and CMs repeatedly articulated a need for improved financial and other supports, which might include direct cash transfers, child welfare grants or salary. Volunteers mentioned the need to balance their donated labor workloads with their need to earn their own household income. CMs suggested that

[215] Ibid

incentives such as higher salaries or increased vacation time would be supportive measures. Both volunteers and CMs expressed interest in opportunities to grow professionally through additional training and feedback on their performance. CMs also suggested creating standards for client loads to help protect caseworkers from burnout.

Food and Nutritional Support for HIV-Positive Clients and Their Children: An overwhelming number of HIV-positive clients identified food assistance and other supports for their children now and in the event of their death as their number one concern. They also noted their need for such basic essentials as soap and body cream. Health care providers, CMs, referral partners and volunteers reiterated the need for more adequate food supplies to be integrated into service delivery goals.

Inadequate Program Resources: A full 79 per cent of CMs interviewed said they felt they had insufficient resources to carry out their duties. FOSA health providers acknowledged the value of the program but said they felt that CMs and volunteers should be equipped with resources to regularly distribute to clients, such as food packets, soap, sugar or flour.

Transportation: The challenge of transport to and from medical facilities was cited as an impediment to receiving and providing needed care. Health providers, CMs, referral partners and volunteers reiterated this need. Support for transportation would enable CMs and volunteers to reach more clients per day. Potential suggested solutions include providing resources for fuel and bus fare, and hiring CMs who have motorbike licenses or bicycles.

Simplify Administrative Tasks: CMs said they perceive the client intake and assessment forms as being “too long” and time consuming to complete considering the number of clients under their care. Burdensome paperwork resulted in delays in the development of individualized plans.

Referral Tracking Systems: Staff reported that comprehensive client tracking and monitoring would be useful for monitoring client progress. A tracking system for referrals should be developed that would allow a CM to determine if a client and his/her family has successfully interacted with local referral organizations. A tool that is short, easy to use, and tailored to the local context is necessary to ensure that thorough, accurate records are kept of client and program activities.

Improved Monitoring & Evaluation: Improved monitoring and evaluation systems would help to quantify the impact CMs are having on clients and their families and provide more insight into program challenges.

Program Case Study 4: Partners in Health Rwanda: Building an Integrated Rural HIV/AIDS Treatment and Health Care System in Rwanda

[Note: Unless otherwise cited, the information in this section was garnered from the PIH website—pih.org—which offers generous accounts of its global programs, challenges and successes.]

With a population of 8.2 million, Rwanda faces a generalized epidemic, with an HIV prevalence rate of 3.1 per cent among adults ages 15 to 49. According to UNAIDS the prevalence rate has remained relatively stable, with an overall decline since the late 1990s partly due to improved HIV surveillance methodology. In general, HIV prevalence is higher in urban areas than in rural areas, and women are at a higher risk of HIV infection than men. Young women ages 15 to 24 are twice as likely to be infected with HIV as young men in the same age group**.**[216] Rwanda is among the world's least developed countries ranking 158 of 177 in the United Nations Development Program's 2006 Human Development Index. Some 60 per cent of the population lives in poverty and average life expectancy at birth is only 38 years.[217] During the three months of the 1994 bloody genocide that rendered an estimated 800,000 dead, incidences of mass rape, sexual torture and psychological trauma were common and significantly increased the number of HIV infected, particularly among women and girls. Recognizing the tragic ties between the genocide and the current AIDS epidemic, the Rwandan Ministry of Health has been one of the most aggressive in Africa in extending HIV treatment to its neediest and most vulnerable populations. Rwanda's National Policy on HIV/AIDS states that the nation's first cases of HIV/AIDS were diagnosed in 1983 at the Centre Hospitalier de Kigali. Realizing that the health sector alone could not adequately respond to the disease, the government committed itself to a multi-sectoral approach and created the National AIDS Control Commission (NACC) through a Presidential decree. Section 2.2.c of the National Policy on HIV/AIDS states *"care and support to HIV/AIDS is an action based on a multi-sectoral, multi-dimensional, community-based and decentralized approach."* The document further explains government commitment toward strengthening home-based care, providing durable nutritional support for children in need and for infected and affected persons through income generating projects.[218]

Like many nations in Africa, Rwanda suffers from an acute shortage of human resources throughout its health care sector, which is a significant constraint to scale up. Of Rwandans killed or displaced during the genocide, a disproportionate number were highly skilled and educated members of society, including doctors, nurses and other

[216] UNAIDS, Report on the Global AIDS Epidemic, 2006.
[217] United Nations Development Program, Human Development Index, 2006.
[218] National Policy on HIV/AIDS, National AIDS Control Commission, Office of the president, Republic of Rwanda, pg. 15 and 16. No date.

health workers. Many health centers in Rwanda lack essential physical facilities, equipment and supplies. Erratic electricity supply is rampant throughout the country and impacts hospitals, health centers and laboratories, as well as blood safety, data management and drug storage. While stigma continues to be a problem for PLWHA, appears that the situation is slowly improving due to improved information sharing at all levels about the pandemic.

Rwanda is one of 15 focus countries receiving aid from PEPFAR. The Government of Rwanda received US$39.2M in 2004, US$54.9M in 2005, US$72.1 in 2006, and approximately US$103M in 2007 to support comprehensive HIV/AIDS prevention, treatment and care programs. In 2008 it is slated to receive US$123M.[219] The PEPFAR response in Rwanda calls for:

- Building human capacity, including training medical staff and building capability in an evolving decentralized health care system.
- Engaging new partners.
- Supporting mass media and faith-based campaigns addressing HIV risk.
- Integrating HIV prevention activities with community-based care programs.
- Assisting national drug procurement efforts to improve procurement procedures, storage and distribution, quality assurance and control systems, physical infrastructure and information systems.
- Supporting the National Tuberculosis (TB) Program to integrate TB and HIV services at health facilities throughout Rwanda.
- Rebuilding and improving health clinics to provide ART.

A Government-Medical NGO-Community Health Care Partnership

Partners In Health (PIH) is an international health and social justice organization with projects in Haiti, Lesotho, Malawi, Peru, the Russian Federation, Rwanda and the United States. Its global "health-as-a-human-right" mission is enhanced by and benefits from longstanding ties to Harvard Medical School and one of its teaching hospitals, the Brigham and Women's Hospital, as well as newer affiliations with the François-Xavier Bagnoud Center for Health and Human Rights at the Harvard School of Public Health. Like AMPATH, these academic alliances enable PIH to translate its experience serving the destitute sick into clinical and operational research, education and training paradigms, as well as programs and policies that reduce health disparities and improve treatment results. PIH first earned the respect of global health advocates through its twenty-five year old comprehensive HIV/AIDS prevention and treatment program in rural Haiti. It is known throughout the world for its commitment to caring for all patients regardless of their ability to pay, alleviating the root causes of disease—including poverty—, fighting for the rights of the poor to have access to life-saving HIV/AIDS and TB drugs, and generously sharing lessons learned.

[219] The United States President's Emergency Plan for AIDS Relief, 2008 Country Profile: Rwanda

Working in conjunction with ministries of health, international institutions and other non-profit organizations, PIH is committed to stemming the tide of childhood death and disease. From experience in Haiti and now around the world, it knows that community-based health-related services linked to excellent clinical and socioeconomic resources offer best chance of improving family and child health. According to Paul Farmer and Jim Kim, co-founders of PIH, *"without a community-based, comprehensive strategy, efforts to treat children–and subsequently mothers, fathers and siblings–fail to provide the desired outcomes."* [220]

Based on PIH's historic success, in 2005 the Rwandan Ministry of Health, with support from the Clinton Foundation, invited PIH to bring its tested health-care delivery model to Rwanda, where limited HIV/AIDS treatment was concentrated primarily in the capital city of Kigali. The first two of six designated health clinic sites were Rwinkwavu and Kirehe, which served a population of close to 500,000 people but had no medical doctor to treat them. Rwinkwavu Hospital had been in a state of severe disrepair for years, and was staffed by only a handful of nurses equipped with grossly inadequate medical supplies. Within weeks of their arrival, PIH and its local partner, Inshuti Mu Buzima (IMB), constructed consultation rooms, hired nurses, restored electricity and running water, and procured basic medical equipment. Eight months later, in districts where few people had been tested for HIV and almost no HIV-positive patients were on treatment, PIH/IMB tested more than 30,000 people and enrolled nearly 700 on ART. Within two years more than 2,500 HIV patients were enrolled on ART, more than 800 villagers—many of whom are HIV-positive—were trained and hired as CHWs and nearly 100,000 patients visited the hospital. The program also provided comprehensive care for children with HIV/AIDS, enrolling more than 150 on lifesaving ART while also instituting comprehensive PMTCT programs at all six clinical sites in 2006. In its first year hospital reconstruction generated five dedicated inpatient wards with more than 80 beds, a general pediatric ward, and a separate inpatient center for children suffering from severe malnutrition. With Rwinkwavu Hospital as its main referral site, PIH/IMB continues to expand and now offers:

- Comprehensive HIV and TB prevention and treatment programs.
- Ambulatory primary care services.
- Prenatal care.
- Family planning.
- Malnutrition programs.
- Maternity and emergency obstetrical care.

Working in four health centers in Kirehe health district, PIH/IMB recognized the desperate need for a hospital that could serve a population of more than 350,000 people. In 2007 it committed to building one with the Ministry of Health and today clinical and laboratory facilities and staff have been expanded. With support from the Bill & Melinda Gates Foundation, ground has also been broken at Rwinkwavu for a training center where educational sessions will be conducted not only for PIH/IMB personnel but for Ministry

[220] Farmer, Paul; Kim, Jim; *Human Rights, Community-based Health Care and Child Survival*, 2008.

of Health staff from throughout Rwanda and for delegations from other African countries.

Bringing the PIH/IMB Human Rights-based, Family and Community-Centered Model to National Scale in Rwanda

Riding this momentum, PIH/IMB, the Rwandan Ministry of Health, the Clinton Foundation and the GF subsequently committed themselves to making the PIH/IMB approach the model for Rwanda's National Rural Health System. With plans to focus on the most needy districts first in 2008, over time all 27 districts and 9 million residents of rural Rwanda will have access to ARVs and comprehensive medical services, including food and nutrition, education for children, and income generation support. PIH/IMB's chief strategy for scaling-up integrated health care services nationally is training Rwandans to replicate the model, thereby creating a critical mass of trained health care professionals who can teach and implement the model in all regions of the country. PIH/IMB aims to serve primarily as facilitators, assisting the Rwandan government to meet its own national health goals. Scale-up and health care implementation will occur on four ongoing levels: District Hospitals, Health Centers, Health Posts and through the vital work of paid CHWs situated in each village and community. The Rwandan Ministry of Health is extremely committed to ensuring that PIH's comprehensive, family-centered holistic approach—known throughout the world for considering the dignity of the patient and their family—is adopted as the medical norm in Rwanda.

Program literature from the PIH website describes the building blocks of this human rights-based health care mission:[221]

- High quality health care requires a truly comprehensive and integrated approach at all levels.
- A comprehensive supply chain and procurement plan should be in place for drugs, diagnostics and other commodities.
- Patients should be able to access health care without regard to their ability to pay.
- Healthcare workers should be highly trained and compensated fairly.
- All health centers should have decent basic infrastructure and functional equipment to support the services they provide.
- CHWs must be vital components of the health system.
- Nutrition and clean water is an essential element of any comprehensive health care service.
- Information and communication technology should be integrated into existing health systems to improve the delivery of health care.
- Health institutions should be held to the highest standards of care.
- Comprehensive rural health care must go beyond the purely clinical by providing socio-economic support as well.
- Health care programs must ensure that children have access to education.
- Health care programs must ensure that families have a means to generate income.

[221] Ten Principles of Rwanda Scale-Up, www.pih.org

- Community-based health care delivery models should be decentralized and linked to district and national health and social support systems.

An Integrated Human Rights-based Approach to Health Care

In each setting where PIH has worked, it has learned—like AMPATH and CARE has learned—that health problems do not occur in isolation from other basic needs, such as adequate nutrition, clean water, sanitation, housing and primary education. PIH recognizes that NGOs must collaborate with the communities they serve and with local health authorities to strengthen public health and ensure that future generations regard these services as rights rather than privileges.[222] In an article entitled, *Human Rights: Community-based Health Care and Child Survival*, PIH co-founders Paul Farmer and Jim Kim identify five key components for implementing comprehensive, community-based child survival programs[223]:

1. Work in close partnership with public health authorities to roll out the interventions shown to be crucial to improved child survival.

- Expanded vaccination campaigns.
- Vitamin A distribution.
- The use of oral rehydration salts to treat diarrheal disease and safe-water programs to prevent it.
- An aggressive PMTCT program.
- Malaria prevention with mosquito nets, backed by improved community-based and clinical care.
- Nutritional assistance for children suffering from or at risk of malnutrition.
- Provision of high-quality in-patient and ambulatory pediatric services for those children who do fall ill.

PIH/IMB is working with Rwandan community and government partners to show how an integrated package of key child survival interventions, including PMTCT, can be rapidly deployed under the government's strengthened rural-health-care model. With support from JLICA, PIH and other NGOs and donors engaged in scaling-up child survival interventions in rural districts around the world are openly sharing innovations through a collaborative global network and transparent learning environment. This collaborative learning mechanism will enable providers to improve service quality and reach greater numbers of children and families in previously underserved areas.

2. Knowing that the health and well being of mothers are key determinants of child survival, promote integrated maternal and child health care.

PIH/IMB's work on behalf of children is linked to efforts on behalf of their mothers and other family members through family planning programs, prenatal care and modern

[222] Ibid
[223] Ibid

obstetrics. In addition, PIH/IMB considers efforts to promote adult literacy, poverty alleviation and gender equity as vital components of women's health programs.

3. Initiate and/or strengthen linked pediatric AIDS prevention and control programs nationwide.

In concert with the Clinton Foundation and Rwandan health officials and providers, PIH has launched a major nationwide pediatric AIDS initiative. Quality pediatric services are linked to community-based care for children with HIV and also to prevention efforts within primary and secondary schools in rural Rwanda.

4. Design operational research and training programs to improve the quality of care afforded to rural children.

Such research should examine:

- The programmatic features of successful efforts to prevent HIV transmission from mother to child.
- The diagnosis and management of HIV among infants.
- Pediatric tuberculosis diagnosis and care.
- The role of CHWs in improving care for chronic pediatric conditions, including AIDS and tuberculosis, and preventing, diagnosing and providing home-based treatment for such common ailments as malaria and diarrhea.
- The impact of social interventions, including those designed to curb food insecurity and illiteracy, on the health and well being of children worldwide.

5. Advance these efforts in tandem with those designed to promote basic human and health rights, in particular, the social and economic rights of the child.

PIH/IMB's Program on Social and Economic Rights (POSER) disseminates a rights-based model of poverty alleviation, using access to health care as a means of engaging with the poorest children and families. POSER backs education, agriculture, housing and water projects to guarantee basic social and economic rights for every child and family. Knowing that hunger and malnutrition are the underlying causes of millions of child deaths each year, food must be prescribed as an essential medicine for immunization and pediatric care. Similarly, increasing educational access reduces the risk of HIV infection and other diseases associated with poverty.

The PIH Rural Community Health Worker Model: An Innovative Solution For Human Resource Shortages in Poor Settings

As mentioned earlier in this report, an acute shortage of doctors and nurses plagues many African nations and compromises government efforts to provide essential medical services such as child immunization, care during pregnancy and childbirth, and

treatments for HIV/AIDS, tuberculosis and malaria.[224] Information garnered from the WHO indicates that as a result of national health care system budget cuts and privatization efforts mandated by IFIs in the 1980s and 1990s, thousands of doctors, nurses and pharmacists immigrated to wealthier nations in search of better paying jobs. Today, doctors working in villages in Liberia earn as little at $15 per month. More than four million health professionals are urgently needed in 57 countries, mostly in Africa and Asia. Ethiopia, for example, has 21 nurses per 100,000 people, while the United States has 900 nurses per 100,000 people.[225]

PIH's CHW model, first rolled out in Haiti to ensure poor patients adhered to ARV treatments, is one of its most important and distinguishing program characteristics. At sites in Haiti, Peru, Chiapas, Boston, Rwanda, and Lesotho, CHWs connect clinics with local communities by serving as counselors, educators, treatment providers, and advocates experienced in local needs. By delivering services to patients in their homes, CHWs improve adherence to ARV treatment and reduce the burden of time and money on both patients and overburdened health care systems. Hired from within the communities that PIH/IMB serve, these local workers are highly trained, paid fairly and mobilized to prevent and identify illness, provide counseling to all family members and enhance the delivery of quality health care to the entire family and to the community.[226] CHWs enable health care systems to overcome personnel and financial shortages by providing high-quality, cost-effective services to community members in their homes, and by identifying serious health conditions at an early stage, before they become more dangerous and expensive to treat. CHWs also monitor and advocate for patients' needs for food, housing, and safe water. They lead education campaigns and empower community members to take charge of their own health. By accompanying patients day by day, CHWs develop a deep awareness of the effects of illness and poverty in their community. Because of their local knowledge and personal commitment, CHWs may be able to support their communities to address broader barriers to health, including oppression, violence, and social and economic injustice.

PIH/IMB breaks down CHW duties into the following categories:

1. Provision of Home-based Care

CHWs provide the bulk of daily care to patients, especially those who have chronic illnesses such as HIV and TB. CHWs are responsible for administering all out patient TB and HIV-related medications. They directly observe the ingestion of pills at the same time once or twice a day in the patient's home and record the patient's adherence. By working to ensure that patients adhere to medications, CHWs fulfill an essential function in optimizing patients' clinical outcomes and preventing or delaying the emergence of drug-resistant disease. CHWs also routinely visit HIV-positive patients who are not receiving ART to assess their ongoing needs and those of their family.

[224] Qing, Koh Gui, *Developing World Has Acute Shortage of Health Workers: WHO*, Reuters, April 3, 2007.
[225] United Nations World Health Report, 2006
[226] Farmer, Paul; Kim, Jim; *Human Rights, Community-based Health Care and Child Survival*, 2008.

2. Provide Psychosocial Support to Patients Undergoing Treatment and to Their Families

By visiting patients and their families every day, CHWs are able to witness firsthand the stresses that affect a patient's health status and adherence to treatment. Their knowledge, commitment, and ability to access additional community resources enable them to support the patient and his/her family in important non-medical ways during treatment and beyond. CHWs provide emotional and practical support to patients by reducing their sense of isolation and by encouraging them to discuss their illness with their families. As the main bridge between the patient/family and the clinic, they alert health center staff about the patient's mental, social and economic state. CHWs may also provide counseling and facilitate referrals on mental heath, substance abuse, nutrition, domestic violence and other social issues.

3. CHWs Act as the Link Between the Patient and the Health Center

CHWs are the *eyes and ears* of the clinical team in the community. CHWs accompany their patients to the health center, sometimes assisting with arranging transportation, childcare, or other logistics. At the same time, they advocate for the patient by assessing, monitoring, and attending to patients' need for food, housing, safe water, education, or financial assistance. They notify the clinical staff and the social worker when these non-medical problems impact patients' adherence, treatment or overall health.

4. CHWs Carry Out Active Case Finding

CHW's proximity in the community enables them to proactively identify sick or otherwise needy people, especially family members or other close patient contacts. They often recognize opportunistic infections or TB symptoms and encourage people to be tested and treated. CHWs pay particular attention to groups at higher risk for TB: children, HIV-infected patients and malnourished people. They may also identify social and economic obstacles that impact on health, such as problems with children's schooling, housing or economic hardship, and help to obtain support for these social needs.

5. CHWs Educate the Community About a Variety of Health Issues

CHWs are public health educators, providing accurate information about chronic diseases such as HIV/AIDS and TB. They explain how to prevent them, encourage community members to undergo testing, and correct people's misunderstandings about disease transmission. They also encourage community members to accept and provide support to PLWHA, especially orphans. Beyond AIDS and TB, CHWs formally and informally educate the community on a wide array of health center activities and health topics, ranging from vaccination campaigns to hygiene and sanitation.

The Role of CHWs in ART Administration and Patient Adherence

The side effects of HIV/AIDS and TB medication can be debilitating, and in some cases, even deadly. Improper administration can lead to patient resistance that renders the medication ineffective. Drug therapies must be taken with precise daily regularity and patients must be well nourished in order for them to combat disease. Until only recently some members of the international community and pharmaceutical industry leaders pointed to these logistical challenges as a reason for denying poor people access to life-saving drug therapies. PIH's, and other organizations, success in utilizing CHWs to ensure patient adherence and appropriate nutrition has significantly reversed this trend.

At PIH sites in Haiti, Rwanda, Boston, and Lesotho, all patients beginning treatment for HIV or TB are paired with CHWs. Every day, these workers visit patients in their homes to supervise treatment and ensure they take their medications regularly and correctly. Over time, they teach their patients how to manage complex dosages, cope with side effects, and identify the signs and symptoms of impending illness. This kind of support strengthens the entire family unit by enabling people with HIV or TB to live longer and healthier lives, with less chance of developing resistance to their medications. The CHW accompanies her/his AIDS patients for a consultation with clinical staff two weeks after ART initiation. In some programs, each AIDS patient is assigned to a group based on the starting date of treatment. Groups are assigned to the health center on a specific day of the week, thus allowing for coordinated care and monitoring of patient cohorts. Additional visits are scheduled when a patient is ill and needs to be seen by clinical staff; a CHW identifies a person in the community who shows symptoms of HIV; TB or other illness; a CHW is assigned to a new patient; or the staff at the health center asks to meet with the CHW. Accompany pregnant women enrolled in the PMTCT program for their monthly consultations.

PIH Fair Pay Policy: Local Job Creation Combats Local Poverty

PIH provides and advocates for professional treatment of CHWs—including fair payment, ongoing training, and provision of necessary supplies—so they can perform their professional duties to the highest standards. Payment to CHWs directly benefits the health and welfare of the community by providing a source of income for people who are often HIV-patients themselves, and who are at risk of disease from hunger and other symptoms of poverty. In some communities, training and employing CHWs makes PIH/IMB the largest employer and source of adult education in the village. In determining how much to pay CHWs, PIH relies on local pay scales for public sector employees, from schoolteachers to staff at health facilities. When a new CHW program is established in an area where community health workers already exist, the payment for both groups are harmonized as much as possible. Other considerations include the extent and scope of the CHWs role, including whether the job duties are considered part-time or full-time. Some programs provide a flat fee to CHWs (Haiti) while others determine salary based on the number of households served and the number of visits the CHWs make to the health centers (Rwanda).

Rwanda CHW Base Payment: Payment depends on the number of *households served*, not the number of patients a CHW supports. A CHW can have a maximum of eight patients in a total of four households. More than one worker cannot visit the same household.

One household:	8,000 FRW (US$15)
Two households:	11,000 FRW (US$20)
Three households:	14,000 FRW (US$25)
Four households:	17,000 FRW (US$30)

Additional Payments: CHWs at PIH/IMB also receive additional payment for overseeing patients in the following categories:

Pediatric Patients:

- 2000 FRW (US$4) when the CHW attends the health clinic with a pediatric patient during a monthly visit.
- An additional 2000 FRW (US$4) is added for each pediatric patient if the patients are in different groups, requiring the CHW to visit the clinic more than once each month. AIDS patients at PIH/IMB are assigned to a group based on the starting date of treatment. Each group is assigned a specific day of the week for the clinic visit to allow for coordinated care and monitoring of patient cohorts.

HIV-Positive Pregnant Patients in the PMTCT Group:

- 2000 FRW (US$4) when the CHW visits the clinic with a PMTCT patient taking ART.
- An additional 2000 (US$4) is added for each PMTCT patient if the patients are in different groups, requiring the CHW to visit the clinic more than once each month.
- An additional 1000 FRW (US$2) is added if a CHW brings a PMTCT patient to the hospital to deliver her baby.

TB Patients:

- 2000 FRW (US$4) because a CHW must come twice a month to get medications.

Deducting Pay from CHWs:

- 1000 FRW (US$2) if a CHW does not bring all remaining pills and treatment cards to each clinic visit.
- 2000 FRW (US$4) if a CHW does not attend a monthly meeting.

Building CHW Teams in Resource Poor Settings:

Recruitment: Based in the Community, for the Benefit of the Community

PIH/IMB's CHWs are always recruited from the communities they serve. In order to identify prospective workers, PIH invites recommendations from respected members of the community such as village elders, spiritual leaders, nurses and teachers. Some

programs organize community, church or school meetings to identify CHWs, while others advertise through local newspapers and radio announcements.

PIH/IMB recruitment criteria includes:

- The CHW must be an adult (usually over 18 years of age) and preferably literate.
- Motivation and character are critical requirements. A CHW must be a trustworthy and respected member of the community with a strong desire to help the needy and a strong sense of empathy with those who are vulnerable and sick. A CHW's work is not only focused on improving health status, but also on social justice and solidarity with the community, through working to support affected individuals and households and reduce social isolation.
- Since the CHW is in daily contact with patients in their homes, he or she should live in or close to the community served. In some cases it is necessary for the CHW candidate to have lived in the community for a specific number of years.
- The CHW should have a background similar to those of the patients they serve so that they feel comfortable sharing their concerns. This familiarity often enables the CHW and patients to more openly discuss concerns and allow the CHW to have first-hand knowledge of the problems and obstacles patients face every day. In some cases, CHWs are themselves HIV-positive or former TB patient and they frequently know someone who has HIV or TB in their community. A CHW cannot live in the same house as the patient, be a very close relative of the patient, or be someone who has been convicted of a crime or accused of stealing.

Usually the clinical team consisting of doctors, nurses, social workers or program managers interview those who wish to apply for the position of CHW. The candidate may be asked to take a basic literacy test, be called upon to read a medication label or write his/her name, distinguish medications by color and size and to count the number of pills in a month's supply of drugs. In some programs, preference is given to candidates who are extremely poor and could therefore particularly benefit from additional income and skill training. Given the specific vulnerabilities of women in the context of the HIV epidemic, women may sometimes be preferred over men.

Training CHWs

In addition to ensuring health-related training, CHW trainings are geared toward instilling a sense of solidarity and social justice in supporting patients, households and the community. CHWs receive an orientation from the clinical staff at the health center and participate in a rigorous training program designed by PIH. Specific goals include:

- Providing correct information about treatment, prevention, and risk factors for HIV, TB, malaria and other infectious diseases.
- Defining CHWs' roles and responsibilities to patients, their families and the community.
- Helping CHWs recognize and reduce stigma and discrimination in their communities.

- Developing CHWs' competence to actively identify disease and socioeconomic needs in the family and community.
- Improving CHWs' communication and psychosocial support skills.
- Directing and linking CHWs to additional resources or to health center staff and members of the community who can guide or assist them in their work.

PIH's current pilot curriculum for CHWs comprises 15 units, with a focus on AIDS and tuberculosis. The training is delivered over seven consecutive or separate days. Each training day consists of 6.5 hours of training, one hour for lunch, and two 15-minute breaks. The number of participants varies according to need but 25 or fewer students are ideal. All participants are provided with meals and a stipend. Based upon adult learning principles, the CHW training curriculum incorporates a variety of participatory pedagogical approaches that build upon trainees' existing knowledge, skills, and experiences. This includes large-and-small group activities and discussions; role playing; case studies; brainstorming; panel discussions; and peer teaching. Trainers and facilitators drawn from a pool of local health care staff should be competent in participatory-based learning methods suited to low-literate adult learners.

After completing the initial training program, CHWs participate in ongoing monthly education sessions for one year and beyond, with additional training in areas such as nutrition, malaria, pediatric HIV/AIDS, diarrheal disease, family planning, active case finding, worms and parasites, chronic disease, first aid, the role of traditional healers, and oral hygiene. New CHWs join with veterans care workers to conduct patient visits. This provides a practical, hands-on learning experience and helps the new CHW develop a support network of fellow peers.

Staff Supervision

Historically, clinic staff, usually a doctor or nurse involved in the care of HIV or TB patients, have directly supervised CHWs. As programs have expanded, however, PIH recognized the increasing need for more formal supervision structures that capitalized on the experience and skills of more senior CHWs. Recently it introduced the role of a supervisory CHW Leader, who is chosen to lead based on the high quality of her/his work, strong leadership qualities and respected standing in the community. The number of CHWs supervised by each leader varies. For example, in Rwanda, leaders supervise between 15 and 25 CHWs while in the Haiti program they may oversee up to 50 CHWs. The primary responsibility of the CHW Leader is to ensure that the CHWs are visiting their patients daily, administering medications correctly, and vigilantly monitoring patient health. The leader also assists the clinical team by answering patients' questions, joining the team on patient visits, and identifying problems between CHWs and patients. In such situations, the leader and other members of the health center identify problems between CHWs and patients through unannounced visits to patients' homes. When a conflict does arise, the CHW is called to the health center to discuss the situation. Leaders meet regularly with health center staff to exchange information and discuss common issues.

PIH/IMB Family and Community-Centered Health and Socioeconomic Care Programs

ART Access: Today, an estimated thirty per cent of the world's population lacks access to basic essential medicines. This figure climbs well above fifty per cent in the poorest regions of Africa and Asia due to a combination of factors, including lack of basic health infrastructure, prohibitive costs, and patent barriers. For more than two decades, PIH has worked to address this stark inequality, acting upon an ethical imperative to supply life-saving medicines and supplies to patients living in rural Haiti, Peru, Mexico, Russia, Rwanda, Lesotho and Malawi. PIH has proven that it is not only technically feasible but also cost-effective to deliver state-of-the-art treatment in poor countries. One of the keys to PIH's ability to deliver quality health care and medications has been establishing an effective system for procuring, managing and distributing essential medicines and supplies. The nature and success of this system lies in PIH's commitment to understanding the specific needs of a community and building on local resources. It also rests in its long-standing relationships with international medical suppliers and manufacturers that provide low-cost, high-quality generic products, most notably the International Dispensary Association based in the Netherlands. In addition, PIH continues to collaborate with the WHO's Green Light Committee and the GF in their respective efforts to bring disease-specific drugs to the world's poor. When PIH speaks of procurement it refers specifically to obtaining medicines and medical supplies, which falls under the auspices of the PIH Procurement Department. As a matter of principle and policy, PIH does not charge patients for medications. The structure and procedures of the department have evolved within an organization based in the United States that supports purchase and delivery to multiple sites in developing countries.

Psychosocial Support for Children: In addition to enrolling HIV-positive children on ARVs, PIH/IMB offers them and their families the opportunity to meet for monthly pediatric counseling groups, where PIH local staff members provide education and psychosocial support. Around Rwinkwavu, staff and patients conduct HIV education programs at local primary and secondary schools, with plans for expansion to additional sites.

Nutritional Support for Patients with HIV and TB and their Families: There is a well-known saying from the PIH program in Haiti that *"to give medicine without food is like washing one's hands in the dirt."* Like AMPATH, PIH/IMB recognize that food security and proper nutrition are essential to successful ART; both are necessary to restore the patient's immune system to health and to provide sustenance for her/his dependents as well. PIH/IMB distributes 1,500 food packages per month to HIV and TB patients and their families, and has signed an agreement with the WFP for another 1,000 per month. To improve food security and nutritional status community-wide, PIH/IMB partners in the Clinton-Hunter Development Initiative launched agriculture programs in the area around Rwinkwavu to distribute maize and bean seeds, as well as cassava cuttings while providing agricultural training to local farmers.

Supporting Patient's and Families' Social and Economic Rights: Like AMPATH and CARE, PIH believes that poverty and disease must be treated simultaneously. PIH's POSER program provides a range of social and economic supports that complements its overall health-related delivery model. POSER services include distributing food packages to the families of all patients being treated for HIV or TB; building solid houses for patient families living in tumble-downed shacks; subsidizing school fees; and creating local jobs by employing village-based carpentry and metalworking shops to produce supplies for the hospital, health centers and POSER houses. In partnership, PIH and the Rwandan Ministry of Health also supplement the cost of insurance and medical consultation fees for the indigent population and help pay for school uniforms and supplies.

Recently POSER expanded its work to improve access to decent housing, education and opportunities to earn a better living. During the course of 2006, PIH/IMB built more than 35 houses, paid secondary school fees for almost 400 students who would otherwise have been unable to go to school, and established a carpentry and welding workshop that provides both jobs for local residents and furnishings for PIH/IMB clinical facilities. In addition it dispersed 40 microcredit loans to income-generating projects for associations of HIV patients in Rwinkwavu and Kirehe.

Assessing Procurement Needs and Resources: Listening and Learning From Patients and Communities

PIH/IMB establishes the criteria for local service delivery through an ongoing informal process of surveys and meetings with community members to determine their specific needs and desires. As a matter both of principle and effectiveness, PIH insists that programs delivering quality medical care be grounded in a comprehensive assessment and understanding of local conditions, needs, and available resources. This process of listening to and learning from patients and their communities is absolutely essential for accurately defining the requirements and priorities of a functional procurement system. Requirements and implications for acquiring, shipping, managing and delivering medicines and medical supplies need to be taken into consideration as part of a comprehensive assessment that covers everything from local health conditions to national regulations for registration and import of medicines. Areas of critical importance for procurement include:

- *Medical Conditions:* Determining what medicines and supplies will be needed and in what quantities hinges on an understanding of the prevalence and severity of diseases in the catchment area.

- *Personnel:* Procuring and managing stocks of medicines and supplies requires staff with training and responsibility for placing orders, organizing and tracking shipments, and storing and managing stocks.

- *Legal and Institutional Framework:* It is important to be familiar with government rules and regulations and to work closely with the Ministry of Health.

- *Building Infrastructure:* Organizations distributing and storing medicines and supplies need to secure a small warehouse and a pharmacy. Neither needs to be an elaborate facility, but they do need to meet basic requirements for accessibility, security and climate control.

- *Warehouse:* A warehouse must be readily accessible from a road in good enough condition for trucks to deliver supplies. It must be solid enough to protect stock against damage from weather, bugs, rodents and unauthorized individuals. That means, at the minimum, a strong roof, solid walls, a door with a lock, and a floor that stays dry during rainy seasons. The warehouse should be equipped with shelves to keep supplies off the floor and avoid damage in the case of a flood. Narcotics must be kept in a separate locked cabinet that is only accessible to managers. The warehouse should also have reliable electricity for lighting, refrigeration, and computers for tracking inventory. Ideally, pharmacies and warehouses should both be temperature controlled, or at least well ventilated and equipped with exhaust fans.

- *Dispensary or Pharmacy:* A pharmacy can simply be a room with a door that locks. It should have ample shelf space and a window for receiving and filling prescriptions. PIH has found it effective to equip both warehouses and pharmacies with plastic bins that can be clearly labeled and used to hold separate items, shelved in alphabetical order by drug type (oral, injectable, or topical).

Challenges to Scale Up

General Health

Rwanda's rugged, mountainous terrain has earned it the nickname of the *"land of a thousand hills."* It is the most densely populated country in Africa and natural resources are scarce. According to data from UNICEF, more than half of the nation's population is comprised of children and an estimated 810,000 children have been orphaned as a result of the 1994 genocide or from HIV/AIDS. Malnutrition affects nearly a quarter of all children, and is responsible for 40 per cent of all deaths among children under age five. More than 100,000 children are believed to live in child-headed households.[227] Given these and other challenging circumstances, PIH/IMB and the government's ultimate aim of introducing quality HIV/AIDS and general health care throughout the country cannot be achieved without also addressing a host of additional medical, social and economic obstacles. Unlike AMPATH and CARE, no external or internal evaluation documentation was available to assess specific program challenges. However, PIH did list a set of general health and financial factors that impinge on program scale up.

- *Malaria:* Malaria is the overall leading cause of morbidity and mortality in Rwanda, responsible for up to 50 per cent of all outpatient medical visits. Children under five years of age account for 54 per cent of these visits and malaria is responsible for 53

[227] Rwanda Background Information, UNICEF Website:
www.unicef.org/infobycountry/rwanda_1717.html

per cent of deaths in this age group. Rwanda is one of four second-round target countries to benefit from the President's Malaria Initiative, a five-year $1.2 billion program led by USAID, in conjunction with the Department of Health and Human Services, the Centers for Disease Control and Prevention, the Department of State, and the White House. Prevention strategies include insecticide-treated bed nets, targeted indoor insecticide spraying and artemisinin-based drug treatment.[228] The WHO reports that Rwanda had 66 per cent fewer child malaria deaths in 2007 than in 2005. Previously, the Ministry of Health says some 2,000 Rwandans were dying every year of malaria, 30 per cent of them children.[229]

- *Maternal Mortality Rates:* Rwanda's maternal mortality rates are high. WHO 2006 data indicates 1400 women out of 100,000 die in childbirth, or one out of every 25, due to an absence of family planning and obstetric care in rural regions.[230]

- *Tuberculosis:* TB is currently the leading cause of death among Rwandans with AIDS and it kills many others who are not infected with HIV. Data from WHO indicate that TB treatment success rates in Rwanda have increased from 58 per cent in 2003 to 81 per cent by the third quarter of 2006; however, case detection was an estimated 24 per cent in 2005.[231] Based on this data, Rwanda is close to achieving the WHO target for treatment success, but is below the target for case detection. Concerted efforts are being made to ensure that effective smear microscopy and directly observed therapy are available nationwide. Further efforts are needed to reach these goals, especially for case detection. A recent national survey showing that the prevalence of multidrug resistance among new TB patients is 3.9 per cent gives cause for concern.[232]

- *Hunger, Malnutrition and Poverty:* Hunger and malnutrition are the principal cause of death for many Rwandan toddlers. WFP data states that the nation has limited natural resources and one of the highest population densities in Africa—an estimated 310 inhabitants per square kilometer. Ninety per cent of the population depends on agriculture for survival. Small family farming plots, soil infertility, low use of agricultural inputs and erratic rainfall result in chronic and often acute food insecurity. About 10–12 per cent of the population suffers from food insecurity every year. Rwanda is ranked 159 out of 177 countries in the UNDP Human Development Report for 2005. More than 60 per cent of the population lives below the poverty line.[233] The child mortality rate for female children is 195 while that for male children is 211 per 1,000. Preliminary findings of the 2005 demographic and health survey indicate that chronic and acute malnutrition prevalence in children

[228] Country Profile, President's Malaria Initiative (PMI), Rwanda, May 2008 (rwanda_profile.pdf)
[229] Rwanda: Malaria Battle Succeeds, Says WHO, Rwanda News Agency, February 1, 2008, Kigali.
[230] Country Health Systems Fact Sheet: Rwanda, WHO, 2006
[231] Quarterly Report July–September 2006. Kigali: Programme National Intégré de lutte contre la Lèpre et la Tuberculose; 2006.
[232] Umubyeyi, A., Vandebriel, G., Gasana, M., Basinga, P., Zawadi, JP., Gatabazi, J., et al. Results of a National Survey on Drug Resistance Among Pulmonary Tuberculosis Patients in Rwanda, International Journal Tuberculosis Lung Disease, 2007; 11: 189-94.
[233] World Food Program website, Where We Work, Rwanda, www.wfp.org

under five is 45 per cent in girls and 19 per cent in boys. Infant and under-five child mortality rates are still among the highest in the world at 110/1,000 and 195/1,000, respectively.[234]

- *Difficulty Accessing Care and Treatment:* Many barriers stand in the way of poor people seeking medical care: transportation costs, social stigma, lack of information, discrimination by medical personnel and time shortages. Even when treatment is available free of charge, these and other barriers often prevent people from accessing the health care that they need and to which they are entitled.

Human Resources

While the PIH/IMB scale up calls for an estimated 6,000 nurses there are only an estimated 3,000 in all of Rwanda. PIH/IMB intends to bridge this gap by training and employing local villagers to serve as CHWs, the most vital link in the health and anti-poverty success rates of all PIH programs globally. As has been demonstrated in the PIH-Haiti program, hiring from within the local community strengthens family and local economies, improves food security and builds trust and familiarity between patients and health care facilities.

Financial Resources

PIH/IMB estimates the cost of providing a comprehensive model of health care to be $280 million annually, an increase of US$180M.[235] This means the Rwanda government will need to substantially increase its health care spending to US$23 per person. PIH states that while this represents a steep increase in government spending, it pales in comparison to current U.S. health spending of about $6,700 per person. This number still falls below the targets endorsed by the African Union of spending 15 per cent of national budgets to provide essential health services.[236]

[234] Rwanda: Humanitarian Profile, UN Office for the Coordination of Humanitarian Affairs, March 2007.
[235] www.pih.org/inforesources/news/Rwanda_Scale-up
[236] On 26 and 27 April 2001, African Heads of States and governments of the Organization of African Unity (OAU) declared that they would allocate 15per cent of their annual national budgets to health services in order to meet "the exceptional challenge of HIV/AIDS, Tuberculosis and Other Related Infectious Diseases".

Challenges Faced by Case Study Programs Individually and Collectively

Of the four case studies only AMPATH and the CARE CM Model were thoroughly evaluated by outside sources. The lack of similar documentation for PIH and the CARE 5x5 Model made it difficult to compare and analyze across programs. Despite these limitations, however, it was possible to at least generalize to some extent common barriers to scale up and program efficiency.

AMPATH:

Three AMPATH program evaluations revealed a number of challenges and unmet needs raised by staff, patients, village leaders and policymakers. Of 56 patients interviewed, the two top ranking concerns were economic assistance to help meet basic survival needs and nutritional supports. Other areas of concern are:

- Expand services, especially to remote rural areas.
- Expand treatment to encompass a broader range of health conditions.
- Expand performance measurement and evaluation.
- Expand outreach to those who are too sick to proactively seek care.
- Strengthen institutional partnerships.
- Strengthen the role of government leadership in AMPATH activities.
- Strengthen staff capabilities.
- Strengthen relationships to other HIV/AIDS programs in country.
- Strengthen relationship to MOH and other GOV leadership.
- Improve efficiency and capacity at all AMPATH sites.
- Improve records system.
- Improve programs for children.
- Improve transportation among sites.
- Improve access, including transportation assistance.
- Provide more HIV prevention and screening.
- Provide more individual and village education.
- Provide incentives (economic and otherwise) to strengthen village- based service delivery.
- Emphasize sustainability and economic development.
- Focus more on at-risk populations.
- Increase community engagement and mobilization.
- Assure AMPATH's sustainability.
- Maximize AMPATH's unique contributions to all HIV programs in Kenya.
- Conduct policy-relevant operations research.
- Enhance local MOH site development.

- Communicate and disseminate information.
- Develop less resource-intensive models of HIV care.

CARE CM:

A thorough program evaluation conducted by the University of Rwanda School of Public Health revealed the following major challenges to efficient operations and scale up:

- Inadequate compensation (or some form of direct cash or in-kind payment) and/or incentives to volunteers.
- A need to increase case manager salaries.
- Expand food and nutritional support to HIV-positive clients and their children.
- Address the need for more program resources, including home-kits that CM could bring to patient's homes that might include sugar, flour, body crème or other essentials.
- Expand transportation and explore transportation voucher systems.
- Simplify and streamline administrative tasks and forms.
- Implement and expand referral tracking systems that are easy to use and monitor.
- Improve program and patient monitoring and evaluation processes.

PIH/IMB:

No program evaluations were available to assess challenges and unmet needs in Rwanda. However, PIH does list as challenges to scale up general categories of concern, such as serious health threats, barriers to treatment and care access and limitations in human and financial resources.

- Malaria.
- Maternal Mortality Rates.
- Tuberculosis.
- Hunger, Malnutrition and Poverty.
- Difficulty Accessing Care and Treatment.
- Human Resources.
- Financial Resources.

CARE 5x5 Model:

No information available.

Intersecting Points of Concern

As the case studies illustrate and numerous other research indicates, HIV/AIDS programs throughout Africa are plagued by staff shortages, inadequate funding, limited institutional

capacity and a need for expanded referral and linking systems, particularly in rural areas. Several key points of concern were voiced by three of the four programs studied. These intersecting concerns are: compensation to workers and some form of direct cash payment or in-kind supports to family caregivers, expanding transportation options to workers and patients, expanding economic and nutritional supports to HIV-affected households, and improving and simplifying administrative processes.

Shortages of Trained Staff

The training and compensation of local professional CHWs illustrated in the case studies speaks to the much broader issue of health care staff shortages that plague the developing world, where an estimated four million positions need to be filled. Shortages are especially acute in SSA, the epicenter of the HIV/AIDS pandemic, where 26 million people —65 per cent of the world's total—are infected with the virus.[237] In severely affected countries, death is the major contributor to health care worker shortages. With an average of 600,000 health care workers serving a population of 682 million, SSA has one tenth of the doctors and nurses for its population that Europe does.[238] An assessment of health-care workers' availability against health care system need reveals stark gaps, with an estimated 720,000 physicians and 670,000 nurses needed to bridge the void. [239]

Various factors underlie the causes of this shortage, including low-training capacity, poor working conditions and salaries, attrition and migration out of the health sector or out of the country.[240] In Malawi, a small country in southern Africa, it is estimated that a full ten per cent of health care workers had died from AIDS by 1997. [241] In the 17-country Joint UN Agency and USAID study, the *OVC RAAAP*, multiple governments cited shortages in funds, poor fiscal tracking, inadequate logistical coordination, and deficits in staff numbers and technical capabilities as reasons why vulnerable children were or were not receiving critical services. It is important to note that all four of the case studies featured in this report circumvent this acute shortage by providing extensive training to local workers and volunteers while also offering refresher courses and continuing education opportunities.

Resource Limitations

A comprehensive World Bank study conducted in 2005 assessed family and community-centered care programs/networks operating within eight of the bank's Multi-Country HIV/AIDS Programs (MAP): Burkina Faso, Cameroon, Malawi, Mozambique, Nigeria, Senegal, Tanzania and Zambia. This cross-country research survey revealed three broad categories that reflected general barriers to the establishment of efficient community-

[237] Simon, V., Ho DD, Karim QA, *HIV/AIDS Epidemiology, Pathogenesis, Prevention and Treatment*, Lancet 2006; 368:489-504.
[238] Johnson, J., Stopping Africa's Medical Brain Drain, British Medical Journal 2005: 331-2-3.
[239] Hongoro, C, McPake B., *How to Bridge the Gap in Human Resources for Health*, Lanceet 2004, 364:1451-6.
[240] Ibid
[241] *AIDS in Africa, Country by Country*, African Development Forum 2000, Geneva: UNAIDS; 2000

based health services: human resources, institutional resources and logistics, and referral systems and links. [242]

Human Resources:

- The MAP research found an insufficient number of trained staff capable of delivering high quality services, including nurses, social workers and qualified personnel at the managerial level.
- Limited financial resources made it difficult to adequately train staff, provide continuing education and refresher courses, or offer counseling for community health workers and volunteers.
- Insufficient incentives for volunteers often led to burn out, and a lack of motivation and commitment on the part of volunteers.

Limited Institutional Capacity:

- A lack of transportation for community health workers and volunteers impeded their ability to reach a greater number of and more remote clients.
- There is limited transportation for clients to and from health facilities for routine medical check-ups.
- There is a greater need for monitoring and evaluation methods to ensure quality care.
- There are too few home-based medical kits, educational material and technical supplies.
- There are insufficient logistical resources to implement activities.
- There is a lack of available funds to improve and expand CHBC activities.

Need to Expand Referral System and Linkages:

- There is a lack of coordination of home-based care activities between community-based organizations, NGOs and health facilities.
- There is a lack of reference and counter reference with the health facilities with regard to PLWHA's medical treatment.

Additional categories covered in the research include inadequate ART support, limited support to children in need, stigma and discrimination, poor health education, difficulty accessing medical supplies and facilities, and lack of proper nutritional supports.

[242] Ibid, pg. 11

Recommendations and Conclusion

Integrated health-related service delivery models that address the well being of HIV-affected households meet the physical, mental, fiscal and nutritional needs of all family members, not just those who are ill or vulnerable. JLICA recommends that governments and donors invest in and sponsor more research about the benefits of family and community-centered care, paying particular attention to: 1.) Benefits garnered from built-in and locally sustainable nutritional support programs to ensure ART adherence and combat malnutrition; 2.) The importance of integrating early childhood development (ECD) into existing national HIV/AIDS and educational programming; and 3.) Combating household and community poverty by compensating—either through salaries or direct cash transfers—to family and community caregivers as well as professional community health care workers.

1.) ART Nutritional Supports and Local Agricultural Production and New Markets:
All of the case studies emphasize the vital necessity of prescribing nutritious foods in tandem with ART, ECD or general health-related service outreach. Three of the programs offer agricultural training and seed/fertilizer supplies or loans to enable families to improve and sustain their own food production. This is a critical economic and health tactic given the current global climate of rising food costs and shortages of food stocks. AMPATH more than any of the other programs studied has actively demonstrated the health and economic benefits of investing in local sustainable agricultural production and environmentally friendly agro-technology. Through a variety of agricultural and job training programs it works with small family farmers to increase soil fertility and crop yields. It also offers services to help enhance their ability to select higher market-valued crops and to negotiate the sale of surplus produce to feeding program suppliers that might include the government, the World Food Program or NGOs. In addition to providing support services, AMPATH also purchases directly small farmers a broad range of nutritious foods for the 70,000 patients and families living in its service catchment area.

In a joint Indiana-Moi University report, *Integrating Nutrition Support for Insecure Patients and Their Dependents into an HIV Care and Treatment Program in Western Kenya*, AMPATH explains its rationale for simultaneously providing ART, nutrition support and economic assistance:

"Responses targeting only the rapid scale up of antiretroviral therapy are unlikely to meet the needs of many of the patients being served. It is clear to those on the front line of HIV care in sub-Saharan Africa that food security and poverty reduction are essential components of a meaningful response to the havoc wrought by the HIV pandemic. Medical care is necessary but insufficient while health care attends to all these sectors. An immediate concern that arises when food support is provided to poor populations is the prospect of long-term dependency. It is unrealistic to think that one can feed patients until they have regained their health and then expect all of them to return to their prior means of securing food for themselves and their dependents. In our experience, some of the patients on ARVs are able to return directly to self-sufficiency; but for others food

security remains elusive even when their clinical and immune status has returned to normal. Too many jobs have been lost; too many spouses have died; and too many assets have been eroded for too many patients who were food-insecure even before HIV entered their lives. AMPATH will rely on the increasing strength of its social service program and expanding Family Preservation Initiative (its economic programs) capability to struggle with those families where food security seems like a goal beyond their reach."[243]

CARE, PIH and other HIV/AIDS programs throughout Africa can benefit enormously from studying the evolution and implementation of AMPATH's environmentally friendly, sustainable agricultural programs. As food and transport costs continue to soar, the benefits of purchasing locally-grown foods becomes even more valuable for programs supporting AIDS-affected families and households that face chronic challenges of malnutrition.

2.) Integration of Early Childhood Development Practices into HIV/AIDS Programming:
Though all of the case study programs articulated a desire to address children's needs, only the CARE 5x5 Model consistently implements such practices in community-based child-care settings. These practices, as stated earlier in the report, are vital for healthy child development, particularly among children who have experienced early trauma.

Children's ability to think, establish relationships, and fulfill their own desires and potential is directly correlated to the synergistic connections between good health, proper nutrition, appropriate cognitive, physical and emotional stimulation, and loving interaction with others, particularly a primary caregiver. As stated earlier in this report, a large body of growing evidence has documented the critical relationship between early brain development and the need for overall good health and nutrition.[244] Research from around the world proves that the development of the brain in the early years of a child's life affects physical and mental health, learning and behavior patterns throughout the life cycle. Research shows that children who are well nurtured during their early years tend to perform better in school and have a better chance of developing the skills required to contribute productively to the social and economic development of their own lives and that of their society and nation.

Infants and young children ages 0 to 8 who have been affected by HIV/AIDS are among the most vulnerable casualties of the pandemic and meeting their short and long-term needs has only recently become a priority for governments, donors and other members of the international community. Research shows that these children are more likely to endure psychosocial stresses caused by such early trauma as the deaths of family members, lack of a safe home environment, poverty, poor socialization and malnutrition. Very young children affected by HIV/AIDS are more at risk for starvation, poor cognitive and social development, susceptibility to childhood diseases and mortality,

[243] Mamlin, J., et al, "Integrating Nutrition Support for Food Insecure Patients and their Dependents into an HIV Care and Treatment Program in Western Kenya, p. 3, 11, 2007.
[244] *Carnegie Task Force on Meeting the Needs of Young Children,* Starting Points, 1994.

higher school drop-out rates, exposure to crime, child labor, prostitution and HIV infection later in life.[245]

Investing in children's healthy development helps ensures that a nation will thrive economically, civically and spiritually as a society well into the future. Research has shown that children fortunate enough to participate in well-conceived ECD programs tend to be more successful in school, are more competent socially and emotionally, and exhibit higher verbal and intellectual development capabilities during early childhood than children who are not enrolled in such programs. According to The World Bank's website the benefits of ECD encourage greater social equity, increase the efficacy of other social investments, and address the needs of mothers, particularly single heads of households living in poverty. Integrated programs for young children can modify the effects of socioeconomic and gender-related inequities, which account for some of the most extreme cases of poverty. Studies from diverse cultures show that girls enrolled in early childhood programs are better prepared for school and frequently stay in school longer. Community-based early childhood interventions also liberate older sisters from the task of caring for preschoolers and enable them to return to school. Safe childcare facilities in the community setting may also offer business skills training or microfinance services that enable mothers or caregivers to continue earning and increasing family income. ECD interventions coupled with existing national or donor-funded health and nutrition programs greatly increase children's chances of survival while early educational interventions help prepare children for school and provide important peer socialization.

In its *State of World's Children's 2001* report UNICEF asserts that ECD should include all interventions directed at children or their caregivers, preferably integrated as a package of services that support the holistic development of the child and the well being of its family. Community-based services that meet the needs of infants and young children are vital and ECD programming should include health, nutrition, educational components, as well as water and sanitation in homes and communities.[246] *In a World Fit for Children*[247], UNICEF's outcome document from the UN General Assembly's Special Session on Children in 2003, 180 countries agreed that every child should have a nurturing, caring and safe environment to survive and be physically healthy, mentally alert, emotionally secure, socially competent, and able to learn. Noting the value of ECD in accomplishing these goals UNICEF, UNAIDS and the World Bank in 2003 published an important document recognizing the critical need to prioritize and mainstream ECD programming into existing HIV/AIDS prevention and care programs.

The *Operational Guidelines for Supporting ECD in Multi-Sectoral HIV/AIDS Programs in Africa*[248] stresses that ECD must become an essential component of any well-designed, integrated HIV/AIDS treatment and care program and that it must be incorporated through broad-scale interventions to assure the healthy physical, emotional and cognitive

[245] The World Bank Website, Early Childhood Development, web.worldbank.org
[246] *The State of the Word's Children 2001: Early Childhood*, New York, 2001.
[247] *A World Fit for Children*, Outcome Document 2003 UNGASS Meeting, UNICEF, New York, 2002.
[248] *Operational Guidelines for Supporting ECD in Multi-Sectoral HIV/AIDS Programs in Africa*, The World Bank, UNICEF, UNAIDS, 2003.

development of young children. The *ECD Guidelines* were designed to assist policymakers, donors and staff to develop national ECD policies and programs that address the specific needs of infants and young children. The document highlights the economic value and benefits of ECD as a preventative strategy to help minimize a host of related social problems that may emerge later in children's lives. These may include teen pregnancy, social and/or sexual violence, increased risks of HIV/AIDS, drug use and juvenile delinquency and chronic poverty.[249] Overall, the World Bank/UNICEF/UNAIDS advocate for integrating ECD into national multi-sectoral HIV/AIDS programs and linking them to other national development efforts aimed at intersecting ECD and HIV/AIDS prevention, treatment and care for the entire family.

3.) Compensation to Professional Health Care Providers and Cash Transfers, Old Age Pensions or In-Kind Payments to All Community and Family Caregivers: The issue of compensating—either through salaries or direct cash transfers to households—community health workers and family/community volunteers is perhaps the most critical issue raised in this report. These workers—both professionals and volunteer—are the most important link in the chain of successful or failed family and community-centered HIV/AIDS care and treatment. As stated earlier in this report, since the 1980s donors and governments have typically relied on an informal female volunteer force to deliver the range of health care and social services formerly subsidized by the state before the era of structural adjustment.[250] Though extended-family volunteerism remains a strong tradition in African culture, the pandemic coupled with the insufficient national and global responses to it, has eroded critical social and economic structures within families and communities.[251] The burden of care on unpaid female family and community members has exacerbated poverty at the household level and interrupted many women's ability to work for pay outside the home. Direct cash transfers, old age pensions and child welfare grants for families are one way of staving off deeper family financial crisis and preventing burnout among family-based caregivers who are essential lifelines to PLWHA and vulnerable children in need.

In the context of the case studies, CARE was the only organization that did not pay or offer incentives to all of its health care workers /volunteers, either because of fiscal and/or donor restraints or because it adheres to a program philosophy that seeks to build community cohesion regardless of external funder status. These obstacles and/or resistance to paying caregivers for their caring labor are not unique to CARE's experience in Rwanda. High volunteer turn over is a major source of interrupted health care and other service delivery throughout Africa, and national and global debates about caregiver compensation have been ongoing since the pandemic first emerged more than 20 years ago.

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[249] *Operational Guidelines for Supporting ECD in Multi-Sectoral HIV/AIDS Programs in Africa*, The World Bank, UNICEF, UNAIDS, 2003, p. 3.
[250] Sparr, P., 1994, "Mortgaging Women's Lives: Feminist Critiques of Structural Adjustment, Zed Books for the United Nations, pg. 214
[251] Zoll, Miriam, *The Compensation Debate*, MIT Research Fellow, Program on Human Rights and Justice, 2005.

The compensation debate is argued on both sides by governments, donors, NGOs, communities and families. Proponents argue that payment—even small amounts or in-kind support such as transportation or food vouchers—can do much to sustain worker/volunteer motivation and help offset unpaid care worker's household poverty. Those arguing against it caution that payment will erode community volunteerism and program ownership that is both a traditional aspect of African culture and a necessary means for providing long-term care during the duration of the pandemic, whether funding is available or not. In some communities, including those served by CARE's CM Model, the notion of being a paid caregiver—particularly if you are female—is stigmatized and looked down upon. CARE volunteers said they felt the public was suspicious of their motives and activities because they believed they were paid program staff. To address the problem, volunteers suggested that their role be explained to the community through information sessions and brochures.[252]

A 2004 USAID-sponsored study of more than a dozen community home-based care organizations and volunteers in Uganda and South Africa raises important questions about the adequacy and sustainability of care models that utilize volunteer caregivers vs. paid caregivers, and shows how such programs often exacerbate poverty and gender inequity.[253] Although some care programs reported offering incentives to volunteers—such as end of year stipends or treatment assistance for HIV-positive individuals—they were usually considered to be inadequate to meet provider's basic needs. Volunteers said their financial problems are often compounded by the fact that many of them spend their own money to transport patients to the hospital or to buy food or other materials for them.[254]

Donor Reluctance to Provide Funds for Care Givers

The research in Uganda found that HIV/AIDS care organizations appear to be better staffed and more financially resourced than similar organizations in South Africa, where there is a greater reliance on volunteers. The author attributes this difference to the fact that many NGOs are unable to convince donor agencies to provide funding for staff salaries. A care provider at Sinosizo home-based program in South Africa recounted how her organization almost lost the opportunity to receive any project funding when they included a line item for volunteer stipends in their proposal. The donor advised them to remove the cost component or lose the funding altogether.[255] Research conducted by Save the Children in southern Africa in 2005 identified various policy and advocacy bottlenecks that block the flow of money to community based organizations focused on vulnerable children and families. When community groups were asked why so few grant-makers provide them with requested resources, they said they felt that donors assumed they would be unable to account for funds or to deliver services. The community groups

[252] Thurman, T., Haas, L., Dushimimana, A., *CARE Rwanda's Case Management Program: Evaluation Report*, National University of Rwanda School of Public Health, July 17, 2006,
[253] Akintola, O., A Gendered Analysis of the Burden of Care on Family and Volunteer Caregivers in Uganda and South Africa, Health Economics and HIV/AIDS Research Division, University of Kwa-Zulu Natal/USAID, Durban, 2004.
[254] Ibid, p. 26.
[255] Ibid, p. 37.

themselves said they were able to account for the funds and provide the necessary services.[256] A 2004 faith-based study sponsored by the World Conference on Religions for Peace reached the same conclusion: donor perception did not match reality.[257]

As noted by AMPATH, CARE and PIH in this report, inadequate funding for staff has obvious implications for the quality and long-term continuity of community-based care networks throughout Africa. Evidence shows that organizations utilizing volunteers often experience higher rates of attrition. Informants at Sinosizo in South Africa reported encountering problems in recruiting and retaining volunteers for their programs. One issue that aggravates their volunteer attrition rate is the fact that CHWs receive payment for their activities while volunteers do not. Several years ago, the program almost lost all of its volunteers when South Africa's Minister of Health incorrectly announced that volunteers would be paid 1,000 rand per month. It was later revealed that the minister was actually referring to compensation for CHWs.[258]

It is important to keep in mind the gender dynamics at play in this ongoing debate. Because so many caregivers are female, governments and donors often assume that women and girls are innately inclined to nurture and care for the sick and vulnerable and that compensation of any form–-salary, old age pension or child welfare grants—is therefore unnecessary.[259] Pat and Hugh Armstrong of York University and Carlton University in Canada have investigated divisions of labor according to gender roles and between the state and families. In *Thinking it Through: Women, Work and Caring in the New Millennium*, they write:

"There is very little that is "natural" about women's work in general or their caring work in particular. …Women's caring can be understood only within unequal relationships, structures and processes that help create women as carers and undervalue this caring work. Many women who do provide care, providing services such as meal preparation, comforting and cleaning, may not even see this as care because it is so much a part of their daily lives. The state plays a fundamental role in determining how political, material and symbolic resources are distributed and in mediating these resources in the markets, communities, households and individuals…the benefits and negative consequences are unevenly distributed between women and men, and among women." [260]

In 2004, for the first time in the history of the HIV virus, a major global donor acknowledged the necessity of compensating volunteers who care for orphans and other

[256] Foster, G., Bottleneck and Drip-Feeds: Channeling Resources to Communities Responding to Orphans and Vulnerable Children in Southern Africa, Save the Children, 2005.
[257] Foster, G., Study of the Response by Faith-Based Organizations to Orphans and Vulnerable Children, World Conference of Religions for Peace/UNICEF: New York, 2004.
[258] Ibid, p. 38.
[259] Zoll, Miriam, *The Compensation Debate*, MIT Research Fellow, Program on Human Rights and Justice, 2005.
[260] Armstrong, Pat., Armstrong, Hugh, Excerpted from "*Thinking It Through: Women, Work and Caring in the New Millennium,"* York University and University, Nova Scotia Advisory Council on the Status of Women, March 2004.

vulnerable children in need. Responding positively to a Kingdom of Swaziland proposal, the GF initially decided in favor of funding 6,500 care workers US$30 per month—or US$1 per day—over the course of three years. As Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa at the time, said at the International AIDS Conference in Bangkok in July 2004: *"This is truly an astonishing precedent. And I assume that here after, government upon government will do the same. It's possible that the Global Fund will turn out to be the vehicle through which the international community is finally forced to acknowledge the value of women's work in the developing world."* [261]

Four years later, complex negotiations are still ongoing between the GF and the Government of Swaziland. In 2008, according to personal correspondence from Derek von Wissell, National Director of the National Emergency Response Council on HIV/AIDS (NERCHA), what started out as a very simple concept of handing out stipends to women who are caring for "other people's children" was simplistic.

"There was no existing structure within the nation equipped to handle the project. Once inside the communities the government discovered that 'caring' is a wide concept and that many more women than those who were earmarked to receive funds were also caring for children in their communities. The government was also confronted with other volunteer service providers who are not compensated, such as home-based carers, peer educators, PLWHA support groups, cooks at feeding points, etc. In addition, Rural Health Motivators, which is a formally established structure under government since the 1980s, were only receiving US$14 per month. Many disputes arose as to who should receive money. The Minister even announced that he would use the money to increase stipends for the Rural Health Motivators, which was not the intention of the initial proposal at all."[262]

After numerous discussions and consults von Wissell said the government and the GF decided that the potential money would be used to increase the capital available to the rural women caregivers engaged in UNICEF's sustainable livelihood project, a micro credit and savings scheme. That idea was derailed and replaced with the concept of direct cash transfers based on another UNICEF model rolled out in Lesotho. These cash transfers target the rural elderly and the actual delivery of the cash poses huge challenges. The World Bank is investigating social security in the country and this process will probably lead to a consolidation of social grants in principle and practice. The government is concerned about long-term sustainability.[263]

These challenging complexities were further discussed in personal correspondence from Tatjana Peterson, the GF Portfolio Manager for Swaziland. She stated that Objective 3 of the original project proposal from 2004 stipulated that approximately 6,500 caregivers in 360 communities would receive compensation every month for community-centered care

[261] Statement by Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, Delivered at a Press Conference at the XV International AIDS Conference in Bangkok, July 14, 2004.
[262] Zoll, Miriam, Correspondence with Derek von Wissell, Director, National Emergency Response Council on HIV/AIDS, Government of Rwanda, April 2008.
[263] Zoll, Miriam, Correspondence with Tajana Peterson, GF Portfolio Manager for Swaziland, April 2008.

for vulnerable children in need.

"During the first two years of grant implementation, the main problem with this activity was targeting, posing an insurmountable challenge of selecting very few persons and missing the majority of other caregivers who could claim their right to be included in the compensation scheme. Due consideration was given to the likely negative, long term impact on care giving as the funds were simply not enough to cater to all community caregivers. Also, sustainability of the financing after the life of the Round 4 Grant was a real issue as the Government of Swaziland would not be able to absorb the program. One of the solutions proposed to the Global Fund towards the end of 2007 was to utilize the budget allocation for what looked like a more sustainable project…the capitalization of caregivers' groups—a hybrid between the savings schemes and direct funds injection of previously formed associations, as piloted by UNICEF and World Vision respectively. Under this approach, community carers would form associations and open bank accounts, which would then be capitalized to enable the carers to undertake some economic activity that would generate profits for the group. The committee welcomed this approach. However, because the committee wanted to ensure that caregivers who might not be able to form or join an association were also reached, the final strategy included direct cash stipends to individual carers. In preparing for the implementation plan, stakeholders were —again—unable to resolve the selection process for those to receive cash payments and the requisite logistics to manage those payments. As soon as the committee agreed on this option, some 270 women's association were capitalized at an approximate rate of USD $1,000 per association. The target was to reach 1,800 associations by 2010."

Peterson went on to explain that during the Phase 2 review of the grant in December 2007, the GF Secretariat review panel expressed some reservations as to the newly proposed capitalization scheme, and tasked the committee to re-think its strategy regarding the caregivers support as the risks of misappropriation of funds in managing such a scheme were considered considerable. To this day, the committee and NERCHA have been discussing the possible future of this activity and a consensus has not yet been reached. *"We are inclined to recommend the roll out of this activity by supporting the women's savings model currently implemented by World Vision in Swaziland, which does not include a capitalization element in the project design. The consensus on future action has yet to be reached between all actors, i.e. beneficiaries, implementers, Principal Recipient, CCM and the Global Fund, regarding the most effective and sustainable way of supporting the caregivers."*[264]

All HIV/AIDS-affected nations and the NGOs working with them face similar challenges as the Government of Swaziland. There is no doubt that building a national health provider compensation or direct cash payment program is a far more difficult endeavor than determining salary logistics for a limited number of CHWs in a program like AMPATH or PIH. Though more challenging in resource poor and rural communities it is not impossible, as has been demonstrated in cash transfer, pension and childcare grant programs currently operating in more than a dozen Eastern and Southern African

[264] Ibid.

nations.[265] This report presents evidence supporting accelerated investments to provide some form of financial or in-kind remuneration to all family and community-based caregivers and health care providers. The JLICA report on cash transfers, *What is the Potential of Cash Transfers to Strengthen Families Affected by HIV and AIDS? A Review of Evidence on Impacts and Key Policy Debates* offers detailed assessments of how similar remuneration programs have already been successfully implemented in Africa, Asia and Latin America. The report provides logistical information about how to build the necessary infrastructure to ensure that households affected either by HIV/AIDS or chronic poverty can receive economic assistance as a form of social protections to meet children's and families' most basic needs. Joint research conducted by HelpAge, the Institute of Development Studies and Save the Children UK shows that children benefit directly and indirectly from cash transfer and old age pension schemes. The research noted that families often use such funds to purchase food, clothes, and seeds and for meeting education and health care costs for the entire household.[266] The research also found that individuals and households who might not qualify for cash assistance might harbor resentment against families and community members who do. Fear of creating dependency was also mentioned as a drawback to donor or government direct cash transfer remedies as opposed to earnings-based solutions like those offered by AMPATH, CARE and PIH.

Common Program Components Among Four Case Studies

In addition to these three key recommendations—nutritional supports to enhance ART and combat malnutrition, ECD for healthy child development and compensation to caregivers—JLICA identified additional shared program components that appear to be essential to the viability and sustainability of the programs studied. Among these are:

Health-Related Care is a Human Right: All of the programs featured in this report abide by a human rights-based approach to care and treatment for the entire family, regardless of their ability to pay. Gender equity, social justice and economic empowerment of the family, community and the health care providers are central philosophic program principles.

Redefining Health-Related Care Delivery: All of the case studies appear to be actively reinterpreting the concept of "health-related care delivery" by extending program services beyond traditional medical models to also include socioeconomic, education and psychosocial supports. AMPATH, CARE and PIH all link medical care and treatment to the provision of nutritious foods and access to life-saving drugs, psychosocial support, education, economic security, legal protections, clean water and basic shelter. As university-affiliated academic medical models, AMPATH and PIH serve as global

[265] Adato, M. and Bassett, L., JLICA: LG1 Paper 6: What is the Potential of Cash Transfers to Strengthen Families Affected by HIV and AIDS? A Review of Evidence on Impacts and Key Policy Debates, DRAFT 2007.
[266] HelpAge International, IDS, Save the Children UK, Making Cash Count: Lessons from Cash Transfer Schemes in East and Southern Africa for Supporting the Most Vulnerable Children and Households, 2005.

educational leaders actively combining innovative models of care delivery with ongoing cross-disciplinary research.

An HIV-Affected Household Approach: All of the programs appear to be dedicated to delivering health-related care services to HIV-affected families as opposed to singling out only HIV-infected family members or only vulnerable children. Research provided in this report offers overwhelming evidence that children's physical and emotional health improves, and that children have greater educational and nutrition access, as a result of this family-oriented approach.

Utilizing Local Social Capital: All of the programs hire and train personnel from within the local community, including some who are HIV-positive. CARE's choice not to pay and/or offer incentives to all of its workers was cited in an external program evaluation as a major cause of high turnover rates among staff and volunteers. The desire to generate local jobs and reduce household and community poverty was cited as an important goal by all programs.

Links and Referrals: All four case studies expressed a commitment to improve their link and referral systems with local community groups and NGOs, and with district level government entities. Each program said it could benefit from improved monitoring and evaluation tracking systems, and expansion of their current linkage and referral systems, particularly in more rural areas. External evaluations from AMPATH and the two CARE programs emphasized the need for some of the community-based and district level government services to also improve and expand. The absence of external evaluations for the PIH-Rwanda program made it difficult to assess the quality of its fledgling links and referral system.

Partnerships with National and Local Government Agencies: AMPATH and PIH's close working relationship with various national and local government agencies appear to have enhanced their ability to deliver quality health-related care and treatment to children and families in need.

AMPATH's 20-year relationship with the Kenyan Ministries of Health and Education has enabled it to cultivate close ties with and rely on highly trained Kenyan medical staff. These in-country professionals have consistently lent their professional expertise and research support to the ongoing efforts of the HIV/AIDS program and the academic partnership between the University of Indiana and Moi University. The program's ability to provide cutting-edge multi-faceted service packages to HIV/AIDS-affected families has garnered the attention of government officials who would like to see AMPATH expand their excellent service delivery outside of its Western Kenya catchment area. Though willing to serve in an advisory capacity to other government programs and NGOs, AMPATH has stated that it is not prepared to expand nationally, nor to pare down existing services in the geographic regions it already serves into order to reach more people outside of its perimeters. AMPATH's strength lies in its ability to be flexible in responding to the needs of its patients and to rapidly develop and implement innovative methods to tackle new problems that emerge. Even with an expanded budget AMPATH

may not be programmatically prepared or philosophically keen on scaling-up to the national level.

PIH, on the other hand, was initially invited by the Rwandan government to replicate its proven HIV/AIDS treatment and care program in a specific geographic region. In less than two years the government invited them to scale-up their operations to develop a national rural health care system that addressed HIV/AIDS and other general health concerns. With funding from the government as well as outside sources, such as the Global Fund, PIH is eager to delve into the complexities of such an endeavor. Its primary focus is to train in-country medical workers and build the necessary infrastructure to enable a rural health care system to take root in a country beset by poverty.

Conclusion

The case studies featured in this report are only four among many dedicated to a growing global effort to promote and invest greater resources in family and community-based approaches to health-related care and treatment of HIV/AIDS-affected children and families. At this stage of the pandemic, the recognition of the value of this local approach by such important donors as the World Bank and PEPFAR comes as a relief to many who have witnessed the heroic efforts of kin and neighbors to provide long-term compassionate care to those in need. There are literally thousands of family and community-centered HIV/AIDS services functioning in Africa today. Some consist of small community initiatives that rely on the constant compassion and donated energy of a mostly female volunteer force that struggles on a daily basis to keep vulnerable children, PLWHA and their own families alive. In many instances an isolated mother or aunt provides care to more than one ill family member and often to more than one orphan. Sometimes grandmothers organize themselves collectively to stretch their emotional and physical energies, and to leverage the impact of their scarce economic holdings on the vulnerable and the sick. Still other programs, like those featured in this report, have been fortunate to receive large funding packages enabling them to rapidly scale up their program size and capabilities.

JLICA believes, and a growing body of research shows, that the vast majority of families and communities provide the best care for children and families affected by HIV/AIDS. The extraordinary 25-year reaction of families and communities to the epidemic, however, must not excuse governments or donors from addressing the complex challenges children and their families and communities must contend with in the face of the epidemic. As the number of children in need increases throughout Africa, Asia and Russia, old and new allies must merge resources to strengthen and integrate key services such as education, health care and social assistance for children; enhance the capacity of families and communities to support the health and development of children; and address the chronic poverty that prevents many families from accessing the services they desperately need.