

Chapter 12. Care and Support

Care and support generally includes both care of people living with HIV and AIDS and of families and children affected by HIV and AIDS. UNAIDS includes in its definition home- and community-based care (HCBC), palliative care, psychological support, carer support, and nutrition support. Among these, HCBC is meant to be the foundation on which national antiretroviral treatment programmes are built (UNAIDS 2009c). Under PEPFAR, the term palliative care covers clinical services for opportunistic infections, social care (community mobilization, leadership development, legal services, linkages to food support and income-generating programs, among other activities to strengthen families and communities), psychological services, spiritual care, and positive prevention efforts (PEPFAR, 2009). A 2004 UNAIDS report estimated that in Africa, only 12% of HIV-positive people in need of home-based care actually received it (UNAIDS, 2004).

The nature of care and support needed to meet the needs of people living with and affected by HIV and AIDS is changing as the epidemic evolves. A growing number of people on antiretroviral therapy requires a growing need for lifetime care, including fighting opportunistic infections, providing palliative care and home-based care (UNAIDS, 2010c). While care and support continues to be highly “gendered” (Esplen, 2009), “there is limited evidence on what works in varied contexts to deliver quality long-term HIV treatment and care” and to scale up these programs (Atun and Bataringaya, 2011: S93). Given the evolving nature of care and the scale up in treatment, “current national HIV policies or strategies may not address many central aspects of care and support” (UNAIDS, 2010a: 109).

“Families and communities, particularly women, whose contributions to the HIV response often goes unrecognized and unsupported – meet most care and support responsibilities” (UNAIDS, 2010a: 109).

In 2008, about 17.5 million children were estimated to have had one or both parents die early of AIDS; 14.1 million of them lived in sub-Saharan Africa (UNICEF, 2010c). Some countries are particularly adversely affected: although the HIV prevalence in Zimbabwe declined from 23.7% to 14.3% between 2001 and 2009, an estimated one in four children is an orphan. It is among the countries with the highest number of orphans and vulnerable children per capita in the world, with a majority between the ages of 10 and 17 (Miller et al., 2011a). India also has a high number, estimated at four million children affected by HIV, with nearly 100,000 children orphaned (Ghanashyam, 2010). Despite the fact that “children who have lost parents to AIDS will need our attention long after rates of new infection go down” (UNICEF, 2010c: 27), “to date, there is an almost total lack of rigorously tested interventions for AIDS-affected children” (Cluver et al., Gay, J., Croce-Galis, M., Hardee, K. 2012. What Works for Women and Girls: Evidence for HIV/AIDS Interventions. 2nd edition. Washington DC: Futures Group, Health Policy Project. www.whatworksforwomen.org

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2012:133). Developing this body of evidence is critical to meet the needs of children affected by HIV.

This section covers what is known about interventions that work in caring for and supporting women and girls in general, both with respect to their own needs in illness and the burden of caring for others who are ill. It also covers the care and support of orphans and vulnerable children, especially the particular vulnerabilities and needs of orphaned girls.

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| <p>A. Women and Girls
B. Orphans and Vulnerable Children</p> |
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What Works in Care and Support

12A. Care and Support: Women and Girls

By all estimates, most care and support is provided in the home and women provide two-thirds or more of that care and support (Ogden et al., 2006; Homan et al., 2005b; Akintola, 2006; United Nations, 2008b; Nyangara et al., 2009b; Surkan et al., 2010). However, this means that one-third of care and support is provided by men, and some have argued that making this more visible can shift gender norms and increase men's involvement (Peacock et al., 2009). The role of fathers, both biological and "social" fathers, in studies and surveys investigating family responses to the care and support of children affected by HIV has been largely ignored (Hosegood and Madhavan, 2010).

"Who cares for the carers, and why is it taken for granted that women provide, and will continue to provide, care and support to family members and loved ones, with no sense of the cost and value of this work to society and the economy in general?"
(Berman 2002, cited in Ogden et al., 2006)

Care and Support Programs Often Rely on Women's Unpaid Labor

While ordinary care for families tends to be considered women's domain in most countries, care and support programs have been built on the assumption that the supply of women's labor is unconstrained and flexible and that women's labor will be adjusted in response to crises or illness (Elson, 1999, cited in Ogden et al., 2006). Due to this pervasive view of gender roles, "home-based care is often perceived as a 'cost-effective response' to the epidemic, yet in reality it is exploitation of women's unpaid labour..." (Esplen, 2007: 20). Thus, care often relies on "women, young girls, and elderly grandmothers who are 'default volunteers'..." (Sepulveda et al., 2007: 193). Between 2000 and 2001, 254 interviews of caregivers in Botswana found that 66% of female

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caregivers were single mothers who provided the bulk of caregiving for their sick children with little or no contribution from fathers, with 21% of HIV caregivers losing pay in order to provide care (Rajaraman et al., 2006).

A distinction can be made between linked and unlinked care, although the two are often used interchangeably in relation to HCBC to refer to both clinical and non-clinical care provided by lay, volunteer or professional providers who are linked to programs and non-clinical care provided by family members who are not linked to programs (Ogden et al., 2006). While a range of organizations are involved in care and support programs, including health facility outreach, NGO-based, faith-based, community-rooted, PLWHA networks and self-help groups, unlinked care is still likely the most prevalent type of care available to people living with HIV and AIDS.

Financial compensation for the labor of women and girls, through reimbursements, stipends, salaries or social protection mechanisms such as pensions, children support grants or cash transfers would go a long way to meeting some of the needs of women and girls (Esplen, 2007). Older women who care for their grandchildren, for example, “may not be physically able to work even if offered the opportunity, nor do most have the capacity to generate income to repay a small loan” (Richter, 2012: 29). In the case of girls, they are often removed from school to care for sick relatives. “This is also a huge economic and social loss, both for them and for their future families” (Paxton et al., 2004a: 2). A study in Tanzania found that mothers and daughters provide most care, with AIDS care reducing time available for food cultivation (Tarimo et al., 2009). A review of cash transfer programs that were not targeted to HIV/AIDS-affected households found that cash transfers demonstrated significant impacts on children to increase school attendance, access to health services and nutrition and could reach the poorest families (Adato and Bassett, 2009). *[See also Strengthening the Enabling Environment: Advancing Education]* Provision of home-based antiretroviral therapy may increase adherence and family support. A study based on interviews with 654 people (72% women) receiving HAART through home-based care in rural Uganda found that most reported positive social outcomes, such as increased family support. Home-based care may have advantages in decreasing barriers due to transport, along with the ability to provide for multiple family members (Apondi et al., 2007).

Older Women Need Additional Support

Grandmothers are often the care providers, however, women often have few or no rights to inheritance and property, which particularly affects older women who are widowed (HelpAge International, 2007). Older women are usually considered beyond productive working age, which impedes their income earning abilities. Lack of education further exacerbates their situation in relation to their male counterparts (HelpAge International, 2007). A qualitative study done in 2003 with elderly respondents (50 years and older) in rural and urban communities in two districts of Uganda highlighted the need for comprehensive interventions to support elderly caregivers of people living with HIV and children affected by HIV/AIDS. There was a general concurrence that caring for orphans

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was more stressful for them especially if the child was also HIV-positive. Most respondents did not feel optimistic about the future and felt that they probably would die sooner than they would have otherwise. While reflecting on appropriate interventions that enable them to address some of the challenges brought upon them by HIV/AIDS, the majority cited assistance with income-generation projects, provision of training programs to enable the respondents to gain better knowledge of best practices of care, and access to protective equipment (Ssengonzi et al., 2007). A cross-sectional study (year not given) with a hundred elderly caretakers of orphan and dependent children, village and church leaders, local administration, government officials, and members of community-based organizations in Kenya showed the rise in the responsibility of the elderly to provide care for the increasing number of dependent children in their households and their challenge to ensure food security. Fifty percent of the elderly caretakers in the study were between ages 65–87 and 56% had 4–10 dependents in their households. Women constituted 86% of the elderly caretakers. Ninety percent of the caretakers reported old age illnesses, stress and morbidity that significantly inhibited their productive capacity. Thirty-one percent of caretakers highlighted that inadequate income was the major cause of food insecurity followed by lack of energy and strength, lack of time, absence of family resource base, and insufficient household labor (Muga et al., 2009).

Family Counseling and Basic HIV Information Could Provide Needed Support

The needs of carers, mostly women, is often overlooked, but as UNAIDS recognizes, “the strains on those caring for people living with HIV are enormous, and without adequate and reliable support the risk of ‘burnout’ is high” (UNAIDS, 2009c: NP). Both the physical and psychological toll of being care providers is often overlooked by women and care and support programs alike. Many are isolated and receive little social support because of HIV/AIDS-related stigma and discrimination. Some experience gender-based violence (Apondi et al., 2007). Among women, fathers or caregivers who are living with HIV themselves, deciding how and when to disclose to children is challenging (Manchester, 2004; Vaz et al., 2010; Daniel et al., 2007). “Mothers who have disclosed their status to their children described how extremely difficult it was for them to do so. They often delayed for some years....” (Daniel et al., 2007: 116). Support to disclose is critical. [See Treatment] In a study in Uganda carried out between 2001 and 2005, HIV-positive parents reported inconsistent advice from counselors on whether to, or when to, disclose to children, with no national or NGO guidelines or training for counselors. Yet HIV-positive children should know their serostatus prior to becoming sexually active. Children’s perspectives on this topic are needed. Family counseling may be advantageous (Rwemisisi et al., 2008). In a study of the Democratic Republic of Congo, only 3% of 259 children, ages 8 to 17, had been told that their positive serostatus. “Upon learning their HIV status, children felt sadness and worry, but also relief,” as they finally learned the cause of their illness and why they needed medication (Vaz et al., 2010: 251).

Many caregivers, whether women or men, lack information about HIV-related illness, basic nursing care, and measures to protect themselves from HIV transmission (Hong et al., 2004). A 2003 to 2004 study of 1,017 people living with HIV in Uganda found that

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47% reported depressive symptoms, with women, those over age 50 and those without income more likely to be depressed. Screening for depression should be incorporated in HIV care (Kaharuza et al., 2006). A 2000 to 2001 study in Chennai, India with 141 HIV-positive women and 215 HIV-positive men at a large tertiary care community based center, YRG Care, which has provided care for over 10,000 people living with HIV, found that women were more likely to be separated, widowed or abandoned, more likely to be unemployed and more likely to have a substantially lower income than men. Women scored lower than men on all items measuring quality of life (such as worry about being able to take care of oneself, having negative feelings) except being comfortable talking to family and friends about their HIV status. HIV-positive women still bear the majority of household caretaking responsibilities and suffer stigma and shame due to their serostatus. With access to ARV therapy, HIV-positive men and women are living longer, making quality of life an important concern (Solomon et al., 2008).

Few Home-Based Care Programs Address the Specific Needs of Women

The evidence base on home-based care is weak. As a recent Cochrane review stated: “Studies [on home-based care for people with HIV] were generally small and very few studies were done in developing countries. There was a lack of studies looking at the effect of home-based care itself or looking at significant end points (death and progression to AIDS)” (Young and Budgeeth, 2011: 2).

Many women cannot afford to visit a clinic or hospital for treatment. Most prefer to be cared for and die in their own surroundings. Women are also concerned about leaving their children alone if they are hospitalized. Likewise, children are put in the position of having to watch their parents and elders grow increasingly sick and die, to intimately handle their bodies, to wonder and worry whether they are “doing it right” or “doing enough,” while at the same time dealing with their sorrow, grief, and facing an uncertain future (Ogden et al., 2004). In addition, women who mother and care for children living with HIV in resource-limited settings face many challenges, ranging from the routine of pill-taking to disturbing discussions on health. One eight-year-old girl said: “Mummy tells me to take my pills, otherwise I will die and to not tell anybody...because it’s AIDS” (Hejoaka, 2009: 873).

Increasing the Role of Men in Care and Support is Necessary

Gender norms keep men from participating more fully in care and support, although some programming to increase the role of men is underway (Gomo, ND). Providing monetary support for men and boys who provide care and support could also expand their participation. However, shifting some of the burden of care to men will be insufficient to “address the profound issues of poverty, strain and hardship of caregiving on families and households. Nor is it likely to meet the ever growing gaps in services and safety nets on the part of governments associated with health sector reforms, decentralization, privatization and cuts to social spending” (United Nations, 2008b: 9). A 2008 study of 31 focus groups with 264 people in villages, health clinics and hospitals in three districts

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in Lesotho to assess HIV/AIDS care from those participating in and potentially affected by health care initiatives found that men stand to lose respect from other men and discretionary time by entering into community home-based care, but stand to gain economically by now working as a remunerated community health worker. While men's participation in community-based home care can alleviate the disproportionate burden of HIV/AIDS care, women stand to lose the benefit of social recognition and may face competition from men for community health worker jobs. Training for male and female community health workers should involve critical reflections on gender roles and responsibilities. More than 70% of men in Lesotho were willing to care for a family member with AIDS in their home with training and support (Newman et al., 2009).

The Financial Toll of HIV and AIDS on Families is Great

HIV and AIDS can take a tremendous financial toll on households. Asset liquidation among AIDS caregivers to cope with the economic impact occurs, first liquidating savings, then business income, then household assets, then productive assets, and finally, land (Strickland, 2004). Profits from sales of assets may offset losses resulting from caregivers (usually women and girls) being diverted from other income-generating activities. Of note, land is the last asset to be sold given its centrality to sustaining women and families (Drimie, 2002, cited in Strickland, 2004). Up to 41% of female-headed households live below local poverty levels and lack resources to buy land or property or develop land allocated to them (UN Habitat, 2002 cited in Strickland, 2004). A study in Botswana found that caregivers spent on average US\$187.17 per month that was not remunerated, exceeding the monthly income of caregivers and any government financial support (Ama and Seloilwe, 2010). Assessment of HBCB programs in South Africa found that poverty is a constant underlying issue for many HIV-affected households (Horizons, 2005).

For those who are linked to programs, a number of studies find that more women than men attend care facilities, reflecting both that women have more access to health services during pregnancy, to obtain contraception or to obtain health care for their children, as well as gender norms that promote health seeking behavior among women (when they are not ignoring their own health to care for others) but not among men. A study in Burkina Faso, for example, confirmed the low presence of seropositive men not only in the consultation rooms of physicians but also for services that provide food, medicine or school supplies. Few men participated in health care facility orientations or support groups for people living with HIV, despite the fact that the 2003 DHS survey of Burkina Faso found that among ages 15 to 49, 1.9% of women are HIV-positive and 1.8% of men are HIV-positive. "Even when seropositive men consent to follow-up, it is widespread practice for women to stand in for their husband, who has stood apart...if his presence is essential...especially in cases of drug, food or other aid distribution" (Bila and Egrot, 2009:857). Women say they do this both to conceal the man's shame and to avoid widowhood.

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Food and Nutrition is a Critical Component of Care and Support

Food prices have increased and energy consumption has declined between 2006 and 2010 in nearly all developing countries, resulting in an additional 457 million people at risk of being hungry and “many more unable to afford the dietary quality required to perform, develop and grow well” (Brinkman et al., 2010: 153S), most affecting people with HIV and TB, as well as pregnant women and young children. The evidence base on “actions aimed at combating the HIV/AIDS–food insecurity nexus...is still thin” (Gillespie, 2006 cited in World Bank, 2007: IV, A). Nutritious food is critical to people living with HIV, who are two to six times more likely to die soon after initiating therapy if they are malnourished (UNAIDS, 2011a). Baseline nutritional status predicts survival on ART (Srasubkul, 2009, Toure, 2008, etc. cited in Tang, 2012). However, “what we don’t know is will interventions to improve weight and BMI [body mass index] prior to or at ART initiation improve subsequent outcomes?” (Tang et al., 2012). Food insecurity can affect ART uptake and adherence as well as jeopardize caregiving (Tang 2012; Maes et al., 2011). HAART improves key nutritional indexes, such as BMI and anemia (Masaaisa et al., 2011), and whether to provide food supplementation to those on treatment “depends on the patients’ diet and food security” (De Pee and Semba, 2010: S313).

For Those Who Test HIV-Positive, What Care Besides Treatment is Needed?

“A different set of questions arises about the management of those who have already been initiated on treatment. How frequently should they be seen? Should their CD4 count be monitored? What tests for toxicity of drugs are required? And should measurement of viral load be made to identify successful viral suppression and failure?” (IOM, 2011: 185). Disclosure may be helping in gaining support – but it can also lead to violence and abandonment (Eustace and Ilagan, 2010). For those who are HIV-positive yet do not yet meet their country’s national guidelines to start ART, mechanisms are needed to best deliver needed packages of care, such as co-trimoxazole preventive prophylaxis, isoniazid preventive therapy, insecticide-treated bednets and nutritional support (Zachariah et al., 2011a). In addition, simple monitoring to follow retention and attrition, both for those not yet eligible and those who have been stabilized on treatment, is needed (Zachariah et al., 2011a). A simple test for monitoring viral load and CD4 counts that could be used by patients at home in low-resource settings is needed (Zachariah et al., 2011a). [*See also Treatment and Preventing, Detecting and Treating Critical Co-Infections*]

Furthermore, people on ART have palliative care needs (International Palliative Care Initiative, Open Society Foundations, 2010). A study in Tanzania found that palliative care intervention was indicated for 378 (51.7%) patients. The majority was female (70.9%). Morphine was being prescribed to 21 patients (2.8%) and ART was being prescribed to 434 (59.4%). In the field of African HIV care where mortality is high, palliative care has been shown to be largely lacking though it continues to be an important part of HIV programs even in the presence of ARV treatment (Collins and Harding, 2007).

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While remarkable improvements have been made for both patients and caregivers with access to HAART, caregiving is still needed. A 2008 UNAIDS review of caregiving in the context of HIV/AIDS concluded that “caregiving must be addressed through a mix of strategies and development lenses, adapted to different social and economic contexts, in order to address the economic, social and psychological burden of caregiving on individuals, families, communities and economies” (United Nations, 2008b: 9). Inputs from governments, as well as NGOs and communities, are needed. The UNAIDS review calls for investment in operational research to “better understand caregiving in the context of HIV and AIDS and to generate strategic information to inform programming” (United Nations, 2008b: 13). A review by the Horizons project called for situational analyses of HCBC programs to assess the “scope, content and quality of services offered in different communities (Horizons, 2005). Further research on cost-effectiveness of HCBC programs is needed to analyze the cost and benefit of participation to households, and referral systems to care and support programs must be strengthened (Horizons, 2005). However, even in 2012, “...there is little science to guide implementation and expansion of programs” (Richter, 2012: 34).

Care and Support is Now Chronic Care

Care and support has evolved since 2005 from addressing the needs of those dying to caring for those with a long-term, chronic, stigmatized disease. Once a patient has been initiated on treatment, there is currently no unified field addressing HIV survivorship, bringing together the fields of clinical, behavioral, public health and health services to improve the quality of life for people living with HIV (Buscher and Giordano, 2010). Continuing support has been shown to be important for the transition to living with and managing HIV as a chronic condition (Seeley and Russell, 2010). However, in cases of treatment failure, palliative care is needed and can be added onto home-based care, decreasing pain, symptoms, patient worry and family worry and increasing quality of life, feelings of peace and planning for the future (Defilippi and Cameron, 2010).

12A. What Works—*Care and Support: Women and Girls*

1. Continued counseling (either group or individual) and related training for those who are HIV-positive and those affected by HIV can relieve psychological distress.
2. Peer support groups can be highly beneficial to women living with HIV.

Promising Strategies:

3. Outside assistance for home- and community-based care programs with household care can be effective in meeting the needs of HIV/AIDS-affected families.
4. Training others, such as men and young people, to provide voluntary home care assistance can ease the burden of home care for women.
5. Access to ARVs may decrease stigma and improve quality of life.

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12A. Evidence

1. Continued counseling (either group or individual) and related training for those who are HIV-positive and those affected by HIV can relieve psychological distress.

- A cluster, randomized, controlled clinical trial conducted in “an impoverished part of southwest **Uganda** that has been severely affected by the HIV epidemic” (Bolton et al., 2003: 3117) found that group interpersonal psychotherapy was highly efficacious in reducing depression and dysfunction. The link between HIV and depression was outside the scope of this study, but will be the subject of a future study. Mean reduction in depression severity was 17.47 points for the intervention groups and 3.55 for controls. Mean reduction in dysfunction was 8.08 for the intervention groups and 3.76 for the controls. Following the intervention, only 6.5% of those in the intervention groups met the criteria for major depression, compared to 54.7% of the control groups. Prior to the intervention, 86% of the intervention group and 94% of the control group met the criteria for major depression. The intervention villages received group interpersonal psychotherapy for depression as weekly 90-minute sessions for 16 weeks. A local person who had received two weeks of intensive training led groups. The group leader reviewed each participant’s depressive symptoms. The participant was then encouraged to describe the week’s events and link these to symptoms. The group leader then facilitated support and suggestions for change from other group members. The trial compared group counseling to whatever is the usual treatment (which was not delineated). Fifteen villages were randomly selected for studying men and 15 were randomly selected for studying women. In each village, adult men or women believed by themselves and other villagers to have depression-like illness were interviewed using a locally adapted Hopkins Symptom Checklist and an instrument assessing function. A total of 108 men and 116 women completed the study. Eight of the 15 male villages and 7 of the 15 female villages were randomly assigned to the intervention arm and the remainder to the control arm. People confirmed of danger of suicide were not enrolled in the study but referred to a psychologist (Bolton et al., 2003). (Gray II) (*depression, counseling, Uganda*)
- Training for HIV-positive people in **Thailand** in 2007 resulted in significant improvements in general health and mental health among 260 participants living with HIV in a randomized, controlled intervention trial. Training sessions delivered over 13 weeks included the topics of HIV disclosure, stress management, medication adherence, prevention of HIV transmission to others, parenting while ill, and plans with family members and children. A US training manual was adapted to be culturally relevant by Thai researchers and health providers. The study involved 507 HIV-positive participants (67.2% women), with 260 participants in the intervention and 247 receiving standard care. A significant improvement was noted in general health along with a significant improvement in mental health among participants in the intervention group over 12 months and a decline in general health, along with a relative decline in mental health among participants in the standard care group was observed based on the Medical Outcomes Study HIV Health Survey instrument and Social Support Scale, and the Thai Family Functioning Scale. Family functioning was positively associated with an individual’s perceived general health (Li et al., 2010d). (Gray IV) (*support, mental health, Thailand*)
- A study in **South Africa** assessed the psychosocial impact of HIV/AIDS on 100 HIV/AIDS-affected educators before and after participation in a training program and found that the program empowered the educators to cope more resiliently with the personal and professional impacts of living and teaching in an HIV/AIDS-affected setting. Prior to participating in the

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training program, a majority of participants reported negative feelings, poor sleeping and eating patterns, fear of stigmatization and social exclusion, and unpreparedness to fulfill professional roles as a result of HIV/AIDS. Participants also expressed concern over the impact of HIV/AIDS on learners and mentioned their obligation to include information about HIV/AIDS in their daily curriculum. Post-training, participants reported perceptions of enablement on a personal and professional level. In addition, participants described themselves in positive terms and noted professional growth. Participants were divided among 10 groups and 92% were female. Educators who considered themselves HIV/AIDS-affected included educators with loved ones, colleagues, or learners who were HIV-positive or who died from an AIDS-related illness and/or taught children made vulnerable through HIV/AIDS. The training program included nine thematic modules covering health promotion, the psychosocial impact of HIV/AIDS on educators, stigma, healthcare, and resilience (Delport et al., 2011). (Gray IV) (*support, psychosocial impact, South Africa*)

- A study evaluated the efficacy of an individualized psycho-education (PE) program in reducing psychological distress and risky sexual behavior and enhancing self-disclosure associated with an HIV diagnosis among attendees of a walk-in non-governmental voluntary counseling and testing (VCT) center in **Nigeria**. Researchers found that at four weeks post-intervention, significant reductions on all measures as well as reduction in risky sexual practices were observed in the treatment group compared with the wait-list group. Treatment group members were also significantly more likely to disclose their serostatus and accept their HIV status as a way of coping, compared with the wait-list group. Ninety-four consecutive individuals were asked to complete a pre-counseling, baseline questionnaire detailing their sociodemographic characteristics, psychopathology, sexual practices, self-disclosure intention and coping behaviors. They were screened for HIV and post-test counseled. Sixty-seven individuals (72.2%) who tested positive were consecutively randomly assigned to one of two groups: a PE program (four 60-minute weekly manual driven sessions) (N=34) and a wait-list (WL) control group (N=33). The major outcome measures used were the Crown Crisp Experiential Index (CCEI), the Beck Depression Inventory (BDI) (Beck et al., 1961), self-report sexual practices in past three months, self-disclosure intention and the brief COPE (Olley, 2006). (Gray V) (*counseling, risk behavior, sex behavior, psychosocial support, depression, Nigeria*)

2. Peer support groups can be highly beneficial to women living with HIV.

- A 2006-2007 study followed 71 HIV-positive pregnant women, attending maternity clinics in **South Africa**, for six months. The study found that mothers in the Mamekhaya program saw improvement in establishing social support, higher rates of attendance at clinic visits (58% versus 36%) and higher rates of testing infants for their HIV serostatus (97% versus 85%) than the group receiving standard PMTCT services. The study compared an intervention of combined peer-mentoring program and an adapted cognitive-behavioral intervention (Mamekhaya) to standard services for prevention of mother-to-child transmission. All mothers received standard care, while 40 mothers additionally participated in the intervention. The program trained HIV-positive mothers, who had recently delivered a child and had used PMTCT services, to mentor an expectant mother. These mentor mothers were trained to provide support through pregnancy and delivery. The mothers in the intervention group attended eight small group sessions conducted by mentor mothers to discuss healthy living (when to take ARVs, dealing with symptoms), feeling happy and strong (dealing with stigma, finding support, coping), partnering and preventing transmission (partner testing, disclosure, partner sex, family planning), and parenting (feeding choice, custody, attachment, testing, postnatal care). Sessions included review of recent experiences, role-playing, teaching and group discussions. All measures were self-reported. There were few differences between the

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intervention and the control groups with regards to positive coping, measures of HIV discomfort, satisfaction with social support or attitudes related to bonding (Futterman et al., 2010). (Gray IIIa) (*counseling, support groups, mothers, South Africa*)

- Thirty in-depth interviews with women living with HIV in **Vietnam** who participated in a support group starting in 2004 that were interviewed again after two years, along with 23 husbands and 18 mothers-in-laws, found that a support group provided a major source of emotional support to the mothers living with HIV, with most of the thirty women learning how to do peer support work, run a business or keep a job. “I have come to life again and don’t suffer from an inferiority complex any longer” noted a 23 year old HIV-positive woman (p. 147). Through the support group, women access information and services, both for themselves and their children. Peer counselors accompanied the HIV-positive women to health facilities in groups of five. Mothers-in-law also learned to change as the HIV-positive women themselves accessed information, services and support: “In the beginning, I had no idea how HIV is transmitted. All of us were very afraid of it...Now I feel so sympathetic to my son and daughter-in-law. I wish I had not been so awful to them” (p. 148). Prior to the support group, their families would not have meals with them, forbade them to touch their own baby and kept the mother’s HIV-positive status a secret from neighbors. Mothers acutely felt stigmatized by health providers. During PMTCT counseling, “nearly all the information given to infected women during counseling was aimed at protecting other people from infection...Very little was explained about the potential risks to their own health or how they could keep healthy” (p.145). Only six of 30 women were given postnatal appointments by health facilities. Women were blamed by in-laws for ‘not being able to protect their husband from social evil behaviors’ or for ‘being a source of transmission to a beloved grandchild’ (p. 145). Families would not spend money on the HIV-positive mother’s care: “Anyway they will die in the future...It’s a fatal disease. So it’s better to use money properly” said one mother-in-law (p. 146). Training was provided to the support group in communication skills (Nguyen et al., 2009). (Gray IIIb) (*counseling, support groups, stigma, mothers, Vietnam*)
- A study from 2003 to 2005 in **South Africa** with 186 women and 64 men, all living with HIV, found that the 27% (52 women and 15 men) who joined a support group had scored better on physical and mental health items than those who did not join a support group. Almost 90% rated that the support group had a positive impact in their lives. The support group also helped with disclosure and had made them more able to access services and information related to HIV/AIDS. The support group may also have made participants feel more in control of their lives, going from being passive recipients of help to becoming active agents (Dageid and Duckert, 2007). (Gray IIIb) (*support groups, disclosure, South Africa*)
- A cross-sectional study of 147 pregnant women living with HIV in **Zimbabwe** found that access to HIV care and treatment was significantly associated with those enrolled in a clinic-facilitated HIV support group, with those in the support group 2.34 times in multivariate analysis to access HIV care and treatment (Muchedzi et al., 2010). (Gray IIIb) (*support groups, treatment, care, Zimbabwe*)
- Evaluation of the mothers2mothers (m2m) program in, **South Africa** found that the m2m program provided a strong continuum of care to the women and infants. Compared to non-participants, m2m participants had greater psychosocial well-being and greater use of PMTCT services and outcomes. Postpartum program participants were significantly more likely to have disclosed their status to someone than non-participants, and to have done so prior to delivery. M2m seeks to reduce PMTCT, empower pregnant and postpartum women to improve their health and the health of their babies, fight stigma and encourage and support disclosure. The program offered education and psychosocial support to HIV-positive pregnant

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women and new mothers, assisted women to access PMTCT services, and followed up to ensure care of mothers and infants after delivery (Baek et al. 2007). (Gray IV) (*PMTCT, support groups, mothers, South Africa*)

- In-depth interviews with 26 women living with HIV in **Thailand** found that the women stated that becoming a member of a support group helped women reverse the stigma of HIV (Liamputtong et al., 2009). (Gray V) (*support groups, South Africa*)
- In-depth interviews with 30 women living with HIV in **Uganda** found that joining support groups with other women living with HIV created a feeling of solidarity that allowed them to come to terms with their HIV status (Medley et al., 2009b). (Gray V) (*support groups, Uganda*)
- A study with in-depth interviews from 2005 to 2006 with 70 participants on treatment in **Uganda** found that participants stated that joining a support group (TASO) “was an important step that gave them access to vital psychological support, medical treatment and food rations, which enabled improved health and recovery of hope” (Russell and Seely, 2010: 377). (Gray V) (*support groups, Uganda*)
- A study with 162 women in **Uganda** found that 30.9% stated that services provided by TASO and their churches enabled them to cope with their situation (Hodge and Roby, 2010). (Gray V) (*support groups, Uganda*)
- A study in **South Africa** based on interviews with 317 pregnant HIV-positive women found that women reported benefiting from a structured support group. Program material for the support group meetings was based on a needs assessment. The meetings provided information on HIV; the emotional experience of being HIV-positive; sharing coping with difficult situations, using role plays; planning for disclosure; what they wanted from their partners; dealing with stigma; and goal setting and future planning. Masters level psychology students facilitated the support groups. Interviewers following the support group sessions found that the women found the support group valuable: “It was a shelter to hide away where I could talk freely. I can tell others now. Now I am stronger, I can stand on my own” (Visser et al., 2005: 339). Another woman stated: “It was a positive picture of HIV. I did not feel alone and embarrassed anymore” (Visser et al., 2005: 339). Role-playing was especially helpful. In addition, the introduction of human rights helped women to realize “that they were not at fault, but that other people discriminated unjustly against them” (Visser et al., 2005: 340). (Gray V) (*support groups, South Africa*)
- A qualitative study of interviews with 75 people living with HIV (43 females, 32 males) from 20 countries, including **Australia, Botswana, India, Kenya, South Africa, Thailand, Uganda, Zambia, and Zimbabwe**, conducted between 1997 and 1999, found that women were more likely to seek peer support than men and that peer support groups were “lifelines” (Paxton, 2002: 563). (Gray V) (*PLHA, support groups, Australia, Botswana, India, Kenya, South Africa, Thailand, Uganda, Zambia, Zimbabwe*)

Promising Strategies:

3. Outside assistance for home- and community-based care programs with household care can be effective in meeting the needs of HIV/AIDS-affected families.

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- A study of six home-based care programs in **South Africa** (year not specified) found that a range of 10 expressed needs of program beneficiaries were met by household members alone, by household members and outside help, and by outside help alone, with some unmet need, particularly for financial aid. The six programs represented programs that work in rural areas and informal settlements. Data were collected through a household survey of 374 clients, focus group discussions with 59 program beneficiaries and 53 caregivers, financial records and service statistics, and interviews with financial officers, program managers and caregivers. The largest expressed need was for emotional/spiritual support through counseling (over 80%), following by physical care, nursing care, chores and information (from 55-70%), transportation, financial aid, family care and legal aid (from 20-35%), and sanitation (around 5%). Beneficiaries looked to outside help particularly for counseling, nursing care, information, transportation, family care and legal aid. They looked least to outside help for household chores. Even with outside help, the study found that household caregivers spent more time per week assisting the person living with HIV/AIDS than the outside caregiver. The qualitative component of the research found that respondents indicated that they had unmet needs related to financial aid, access to medical care and emotional care. (Homan, et al., 2005b). (Gray IIIb) (*community-based care, South Africa*)
- A 2006 study in **China** measuring the effectiveness of a “planting and eating” soybean project to increase soybean protein in the diet of 47 people living with HIV/AIDS, found that after eating soy, 93% felt better, 86% reported less sickness, 61.3% had higher total blood protein and blood white protein and 58.1% had higher blood hemoglobin. Participants received soybean seeds of 320.5 kg and the harvest was 3465 kg four months later. The project included two training courses. The first covered basic knowledge of planting soybean, in addition to assistance during the preparation and planting periods. The second covered nutrition and taught participants how to integrate soybean into their diets. Of the 47 participants, 60% were women. In addition to changing the diet behavior of the participants, the project changed the diet behavior of their family members, as well as other community members. With a harvest output 10 times higher than the original output, the harvested soybeans could be used as seeds for the next season. The participants reported overall satisfaction with the project (Ji et al., 2010). (Gray IV) (*community-based care, food security, China*)
- A study in **China** assessed the living conditions and palliative care needs of 93 end-of-life people living with HIV/AIDS in rural Henan province and found that the Hunan Provincial Government’s policy of treatment and palliative care to have a beneficial impact on end-of-life AIDS patients. Henan’s policy provides free HAART to the rural poor and includes no-cost ARV drugs, no-cost VCT, no-cost PMTCT, no cost schooling to AIDS orphans, and care to people living with HIV/AIDS. The World Health Organization Quality of Life for HIV (WHOQOL-HIV) BREF Chinese Version was used to measure quality of life and the Memorial University of Newfoundland Scale of Happiness (MUNSH) measured subjective welfare. Qualitative interviews and group discussions assessed the specific needs of the end-of-life patients and provided information on the palliative care model. Living conditions of the end-of-life AIDS patients were moderate. Participants recorded high scores for quality of life, social relationships, and spirituality/religion/personal belief domains. (Sheng et al., 2010: 283). Results suggest that care would be improved by assisting the family unit as a whole (Sheng et al., 2010). (Gray IV) (*palliative care, China*)

4. Training others, such as men and young people, to provide voluntary home care assistance can ease the burden of home care for women.

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- A study of Africare’s Male Empowerment Project in **Zimbabwe** from 2003 to 2004 which trained 80 male home care volunteers to provide basic nursing care, infection control, and psychosocial support found that the trained male caregivers reduced the workload of the primary caregivers, who were primarily women. Clients felt that the simple fact that “‘someone cared enough to visit’ was motivation enough for living” (p. 10). Over 80 percent gathered firewood and over 60 percent assisted with gardening and fetching water. Clients and caregivers were found to be supportive of the program, with primary caregivers and clients giving credit to the voluntary caregivers for improving the mental health and physical well being of the clients. While voluntary caregivers assisted with basic household chores, skills that are not traditionally assigned to men such as feeding were less readily undertaken. This project proved successful in increasing men’s acceptance of providing care to people living with AIDS. The study used a questionnaire prior to the intervention and then 18 months later, two focus groups and five in-depth interviews. The male volunteers received training, covering topics such as HIV transmission and prevention, communication on sensitive topics, life planning, basic nursing care and end of life care. Lack of salary presented problems for the men who were looking to offset the time that could have been spent in income generation. Frequent in-service training and monitoring was recommended for home-based care (Hall et al., 2007). (Gray IIIb) (*community-based care, men, Zimbabwe*)
- A Horizons project in rural **Zambia** assessed the strategy of building young people's capacity to provide care and support to people living with HIV and AIDS. Members of youth anti-AIDS clubs in schools and communities were trained as adjunct caregivers, using a locally developed curriculum that allowed them to explore and challenge gendered notions of caregiving, and that emphasized networking with existing resources. Results show that caregiving increased among males (47% to 82%) and females (41% to 78%). Both sexes provided similar caregiving services, including help with household chores and personal care tasks. Youth also undertook activities with children to decrease their isolation, help them stay in school, and reach additional services. While clients and caregivers reported positive aspects of the programme, both reported frustration with the youths' inability to meet material needs. This study demonstrates that trained youth already involved in anti-AIDS efforts can meet a range of care needs and be valuable assets to their community. It also highlights the importance of communicating clearly what youth can and cannot do, ongoing monitoring and support of youth caregivers, and involving community leaders to give youth credibility and access to local resources (Esu-Williams et al., 2006). (Gray IIIb) (*community-based care, youth, Zambia*)

5. **Access to ARVs may decrease stigma and improve quality of life.** [See also *Strengthening the Enabling Environment: Reducing Stigma and Discrimination*]

- A study of 735 treatment-naïve patients from **South Africa**, of whom 518 were women, and who were followed up for 12 months on ART found that their internalized stigma score decreased significantly while on ART. However depression symptoms remained high (Peltzer and Ramlagan, 2011). (Gray IIIb) (*support groups, treatment, stigma, South Africa*)
- A study with 1,454 people living with HIV (72.7% female) from **Lesotho, Malawi, South Africa, Swaziland and Tanzania** found that those taking antiretroviral therapy reported significantly increased life satisfaction scores as compared to those not taking antiretroviral therapy, as measured by the HIV/AIDS Stigma Instrument (Holzemer et al., 2007 cited in Greeff et al., 2010) and the HIV/AIDS Targeted Quality of Life Instrument. Perceived HIV stigma has a significantly negative and constant impact upon life satisfaction (Homes and

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Shea, 1998 cited in Greeff et al., 2010). (Gray IIIb) (*treatment, stigma, Lesotho, Malawi, South Africa, Swaziland and Tanzania*)

12A. Gaps in Programming—Women and Girls

1. Further interventions are needed to provide support (physical, psychological, technological, economic) to caregivers.
2. Interventions are needed to train caregivers on taking care of children living with HIV.
3. The increased vulnerability of female-headed households requires targeted interventions.
4. Interventions are needed to support women living with HIV to disclose their serostatus to their children and families.
5. Interventions are needed to increase access to palliative care.
6. Caregiver training for male and female community health workers may benefit from critical reflections on gender roles and responsibilities.
7. Further interventions are needed to improve quality of life for women living with HIV.
8. Support is needed for religious leaders.
9. Care and support programs should address gender-based violence.
10. Research is needed on treating anemia, malnutrition and other dietary conditions as well as on optimum micronutrients for patients accessing HAART and for patients prior to accessing treatment.

1. Further interventions are needed to provide support (physical, psychological, technological, economic) to patients and caregivers. Studies showed that patients and caregivers have many physical, psychological, and economic unmet needs, with high rates of depression and poverty, and in some cases, rely on their young children or relatives to provide care with no outside support. Some studies show that caregivers suffer from stigma attached to caring for someone HIV-positive. [*See also Strengthening the Enabling Environment: Reducing Stigma and Discrimination*] Some studies showed that women have a lower quality of life than men. A study in a high HIV prevalence area showed that for women, lack of control in sexual decision-making was associated with depression, while for men, intergenerational sex was associated with depression.

- Gap noted, for example, in **India** (Das and Liebowitz, 2011; Steward et al., 2011); **South Africa** (Petersen et al., 2010; Goudge et al., 2009; Sorsdahl et al., 2010; Casale, 2011; Peltzer and Ramlagan, 2011; Schatz et al., 2011; Kagee and Martin, 2010; Ogunmefun et al., 2011; Akintola, 2006); **Mozambique** (Pearson et al., 2009); **Malawi** (Mkandawire-Valhmu and Stevens, 2010; Fan et al., 2011); **Thailand** (Li et al. 2009); **Nepal** (Yadav, 2010); **China** (Lv et al., 2010; Zhou, 2008), **Botswana** (Lawler et al., 2011; Rajaraman et al., 2006; Shaibu, 2006); **Malaysia** (Hasana et al., 2011); **Tanzania** (Marwick and Kaaya, 2010; Pallangyo and

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Mayers, 2009; Nyangara et al., 2009a); **Brazil, India, Thailand and Ukraine** (Skevington et al., 2010); **Uganda** (Maling et al., 2011; O'Hare et al., 2005; Kaharuza et al., 2006; Ssengonzi et al., 2007), **Nigeria** (Abasiubong et al., 2010; Muoghalu and Jegede, 2010), **China** (Jin et al., 2010); **Botswana** (Gupta et al., 2010); and **Jamaica** (Clarke et al., 2010).

2. Interventions are needed to support parents and caregivers on taking care of children living with HIV. Needs include information and training as well as combating stigma and discrimination against HIV-positive children.

- Gap noted, for example, in **Vietnam** (Chi et al., 2010a); **South Africa** (Demmer et al., 2010; Boon et al., 2010a and b; Boon et al., 2009; van Graan et al., 2007).

3. The increased vulnerability of female-headed households requires targeted interventions. Studies found that female-headed households risk losing farmland and property and need targeted interventions.

- Gap noted, for example, in **Kenya** (Yamano and Jayne, 2004, cited in Gillespie and Kadiyala, 2005); **Uganda** (Kanyamurwa and Ampek, 2007); and **Malawi** (Shah et al., 2001, cited in Gillespie and Kadiyala, 2005).

4. Interventions are needed to support women living with HIV to disclose their serostatus to their children and families. Studies found that HIV-positive women found it extremely difficult to disclose their serostatus to their children and to their families and wanted specific counseling to address this need. A study also found that women wanted support on how to talk to their children about the loss of a sibling from AIDS.

- Gap noted, for example, in **South Africa** (Demmer, 2010); and **Uganda** (Rwemisisi et al., 2008; Manchester, 2004).

5. Interventions are needed to increase access to palliative care. Studies found that a significant proportion of patients needed palliative care, which should be integrated into home-based care.

- Gap noted, for example in **Africa** (Downing et al., 2010); **China** (Sheng et al., 2010); in **Tanzania** (Collins and Harding, 2007).

6. Caregiver training for male and female community health workers may benefit from critical reflections on gender roles and responsibilities. A study found that men and women competed for remunerated caregiving, with training needed on gender roles.

- Gap noted, for example, in **Lesotho** (Newman et al., 2009).

7. Further interventions are needed to improve quality of life for women living with HIV. A study found that women with HIV had lower quality of life scores than men.

- Gap noted, for example, in **India** (Solomon et al., 2008).

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- 8. Support is needed for religious leaders** in coping with the many AIDS-related deaths.
- Gap noted, for example, in **South Africa** (Eriksson et al., 2010).
- 9. Care and support programs should address gender-based violence.** [*See also Strengthening the Enabling Environment: Addressing Violence Against Women*] A study of women who received home-based care found that significant numbers experienced violence.
- Gap noted, for example, in **Uganda** (Apondi et al, 2007).
- 10. Research is needed on treating anemia, malnutrition and other dietary conditions as well as on optimum micronutrients for patients accessing HAART and for patients prior to accessing treatment.** [*See also Treatment*] Increased clarity is needed for providers, caregivers and patients on nutritional needs in settings of marked food insecurity. A Cochrane review which included 16 studies with weak methodologies found that “the evidence-base for the specific effect of micronutrient supplements in children and adults with HIV is limited, but sufficient to make some recommendations for practice. In the absence of population-specific adverse effects, there is no reason to decline similar recommendations for HIV-infected populations” (Irlam et al., 2010:16).
- Gap noted in **Brazil** (Silva et al., 2010); **South Africa** (Walsh et al., 2010); **Lesotho** (Makoa, 2011); **Kenya** (Kuria, 2010); **Uganda** (Komwa et al., 2010); and **globally** (De Pee and Semba, 2010; Raiten et al., 2011).

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12B. *Care and Support: Orphans and Vulnerable Children (OVC)*

In some countries, three generations have been affected by HIV (Oladokun et al., 2010a). Even as incidence declines, there is a clear need to continue meeting the needs of children orphaned and made vulnerable due to HIV and AIDS.

Despite the clear need, “...few interventions for children have been formulated, resourced or implemented on a scale commensurate with the impact of the epidemic” (Richter, 2012: 38). Furthermore, “few evidence-based answers are available to a basic question such as ‘What interventions are most effective in improving child well-being?’” (Chatterji et al., 210: 130). Only 15% of families in 2007 caring for orphans received support (UN cited in Richter, 2010). Where governments have been lacking, faith-based and other community-based groups have provided services (Foster et al., 2012).

“Nowadays there is a deadly disease called AIDS. This disease is only treated but not cured. Anyone can be infected – male, female, young, old, rich, poor, educated, uneducated from any country or any religion” — Girl in Zimbabwe between the ages of 10 to 12 (cited in Campbell et al., 2010a: 980)

“Orphaned children are at greatest risk of a compromised future” (IOM, 2011: 74)

Female Orphans and Vulnerable Children Face Specific Risks

“Old problems, such as gender inequality, are exacerbated by HIV and AIDS, with a double jeopardy for young girls, who are more likely to be kept away from school, required to take over household care responsibilities, and diverted to support income-generation activities” (Heymann et al., 2012: 6).

Data from Rwanda and Zambia show that orphanhood, especially if it occurs closer to adolescence, results in earlier sexual initiation (Chatterji et al., 2004). Early sexual debut places girls at risk of HIV, other STIs, and unwanted pregnancies. Further, loss of a parent increases vulnerability to trafficking, child prostitution, and hazardous labor situations (Ayieko, 1998; Human Rights Watch, 2003c), in addition to forced sex (Birdthistle et al., 2008). [See also *Strengthening the Enabling Environment: Addressing Violence Against Women*] These vulnerabilities enhance orphans’ risk for acquiring HIV. A study in Zimbabwe found a greater number of female orphans ages 15 to 18 had higher incidence of HIV infections than their non-orphan peers (Gregson et al., 2005). “...The majority of orphans and children whose parents are HIV-positive or AIDS-unwell are in fact adolescents and have a great need for information and skills on sexual and reproductive health and development. These topics are frequently omitted from OVC programmes...” (Hallman, 2008: 36).

In Zimbabwe, in a sample of 6,791 students (not sex disaggregated, but including girls), of whom 35% had lost one or both parents, orphans, especially those who had lost both

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parents, were at increased risk of early sexual debut, having been forced to have sex, and less likely to have used condoms (Pascoe et al., 2010). Others have not found a universal correlation between female orphanhood and sexual risk: a study based on Demographic and Health Surveys and Multiple Indicator Cluster Surveys in 36 countries found that only in seven countries (Ethiopia, Ghana, Haiti, Malawi, Mozambique, Uganda and Zimbabwe) were orphaned girls significantly more likely to have had sex before age 15 (Akwara et al., 2010).

Girls Who Have Lost Their Mothers Are at Particularly High Risk

A review of households in Uganda between 1991 and 2008 found that children who lost their mothers had one year less of education; those who lost their fathers were significantly more likely to have married earlier (Seeley et al., 2010). Girls who have been orphaned by HIV/AIDS face an intersection of vulnerabilities: As children, they lack the legal rights (e.g., inheritance and property), maturity, and skills to care and provide for themselves. As girl children, they most often do not have equal access to household resources for schooling, nutrition, or health care. When a catastrophic event hits the family, girls are more often the ones who must leave school and take on a greater burden within the home.

A meta-analysis of 19,140 youth compared HIV seroprevalence among orphaned and non-orphaned youth and found that orphans were near two times as likely to be HIV-positive, with significantly greater HIV seroprevalence and greater sexual risk behavior among orphans (Operario et al., 2011). A study of 200 orphaned and non-orphaned girls ages 16 to 19 in Zimbabwe highlighted that maternal care and support is important for HIV prevention. Seven percent of girls in the study had lost only their mother while 20 percent had lost both parents. Female adolescent maternal orphans were found to have more than five times the odds of engaging in sexual activity with their current partner, more than fourteen times the odds of receiving basic needs from their current sexual partner, and nearly five times the odds of acquiring HIV as compared to study participants who had not lost their mothers. The study also found that maternal orphans were less likely to have been physically forced the first time they had sex. This could be because more maternal orphans were intentionally engaging in sexual activity for material benefits and may thus be less likely to have been forced to engage in sex for the first time (Kang et al., 2008). A pooled analysis from sub-Saharan Africa found that in countries with HIV prevalence greater than 5%, among female adolescents, maternal orphans and double orphans – though not paternal orphans – were at increased risk of having started sex (Robertson et al., 2010).

Many Families Caring for Orphans Are Struggling

“I love our goats...they can help us when we don't have money, and we sell them to get money for other things which can improve our lives”

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Evidence compiled during the Joint Learning Initiative on Children suggests that policies, programs and funding should support family-centered services that address material needs, cognitive

— *Girl aged 12 who cares for sick family members (cited in Skovdal et al., 2010b: 12)*

development and psychosocial support Surkan et al., 2010). However, Richter et al. (2010a, Para 1) found that, “reforms in favor of family-oriented HIV interventions have been slow to emerge.” A study in Botswana using data from a 2002 sample of 1,033 working adults found that 37% provided orphan care. Nearly half of working households with orphan care responsibilities reported experiencing financial difficulties, lacking resources to provide basic needs such as food, shelter or transport. Only 42 social workers were responsible for the care of more than 100,000 orphans (Miller et al., 2006; Heymann et al., 2007b). A case control study done in 2007 in Uganda with 369 HIV-positive children (49% female) between ages 7 months to 15 years found that children cared for by grandparents were less likely than those cared for by biological parents to have their immunizations up to date and more likely to have poor nutritional status (Kintu, 2008).

A study of child-headed households in South Africa found that the households needed basic access to food, health and shelter and clothing (Mogotlane et al., 2010). A systematic review which included 25 studies found that sibling caregiving negatively impacts both the sibling caregivers and those cared for, unless adequate adult supervision is provided (Yanagisawa et al., 2010). However, orphans also provide care for their relatives and often express great pride in doing so (Skovdal, 2010; Abebe and Skovdal, 2010). In addition, many MSM, PWID and sex workers have children and these children and their families should not be neglected, but little research in this area has been conducted to date (Richter, 2010). [*See also Prevention for Key Affected Populations and Safe Motherhood and Prevention of Vertical Transmission*].

Family-Based Programming is Preferable

The Joint Learning Initiative on Children and HIV/AIDS, which compiled over 50 systematic reviews by working groups of world OVC experts, contend that the definition of ‘orphan’ leads the international community to assume that these children are without family support. “The UN definition of an orphan, ‘a child who has lost one or both parents,’ distorts the global response to children affected by HIV and AIDS. Instead, “some 88% of children designated as ‘orphans’ by international agencies actually have a surviving parent” (Irwin et al., 2009: 12, based on Belsey, 2008; Sherr, 2008). Studies found that most orphans had some family with which they could live (Meintjes et al., 2010; Csaky, 2009, Richter et al., 2009). Supporting family systems is therefore essential.

Community- and family-based care for orphans are often more cost effective than institutionalization. The cost per child per year for orphan care in institutions ranges from US\$5,403 (with donated food) in Rwanda to US\$1,350 in Eritrea and US\$698 in Burundi. “For most African countries, this cost per child rules out institutions as the

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preferred options for scaling up orphan care” (Csaky, 2009 cited in IOM, 2011: 75). Foster care is a more economic option compared to orphanages (Santa-Ana-Tellez et al., 2011: 1424). A meta-analysis from 21 articles from 2000 to 2010 for low and middle-income countries found that estimated costs for foster care with minimum standards of care ranged from US\$614 to US\$1,921 per child per year (in US2010 dollars), but educational support for primary school ranged from \$30 to \$75 and health interventions to ensure child survival was estimated at \$55 per child (Santa-Ana-Tellez et al., 2011). Given these high costs, little evidence of effective outcomes (Larson, 2010), and the psychological benefits of family based care, experts advise a multi-generational family-centered approach (Tomlinson, 2010).

Progress is Being Made on Education for OVC

A recent review found that the number and scope of existing studies on the educational outcomes of HIV/AIDS-affected children was limited (Li and Guo, 2012). However, progress is noted: among 14 of 16 sub-Saharan African countries with an HIV prevalence of two percent or more, the level of school attendance among children ages 10 to 14 who have been orphaned has increased to near parity with school attendance among children whose parents are both alive and who are living with one or both parents (UNICEF, 2010c). [See also *Strengthening the Enabling Environment: Advancing Education*]

There is Insufficient Attention in Programming for Psychological Care

Parental death is recognized as one of the most stressful life events a child or adolescent can endure... (Hallman, 2008: 38). Interviews conducted in 2005 with orphans and vulnerable children, their parents and caregivers, students and teachers in communities heavily affected by HIV/AIDS in South Africa and Swaziland found that parental death is one of the major causes of disruption of children’s lives (Poulsen, 2006). Programs should also strive to keep siblings together, where possible. A cross-sectional survey in rural China with 124 double AIDS orphans (42% were female) with an average age of 12.4 years and with at least one sibling (69 separated from siblings and 55 living with a sibling) concluded that separation from siblings is associated with trauma symptoms of AIDS orphans who had lost both parents and were placed in group care settings. The study found that the orphans separated from their siblings had significantly higher scores on anxiety, anger, dissociation and sexual distress as compared to those living with their siblings (Gong et al., 2009). A recent Cochrane review, however, found no rigorous studies of interventions for improving the psychosocial well-being of children affected by HIV and AIDS (King et al., 2009 cited in Giannattasio et al., 2011; Engle, 2012). “Although a large number of small-scale programs are run by NGOs for young children, few have been evaluated” (Engle, 2012: 82).

Disclosure is also a difficult issue. Experts have noted that disclosure, though difficult, is important and can determine if a child and family can access support (Kanesathasan et al., 2011). Gradually building a child’s understanding of HIV/AIDS is recommended. One study in Thailand found that when adults were silent on the issue of AIDS with

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children affected by HIV/AIDS, adults contributed to the poor psychosocial health of the children (Ishikawa et al., 2010).

More Effective Programming and Policies for OVC Are Needed

As of 2008, only 32 countries had a national plan of action with benefits for orphans (UNICEF et al., 2008). Yet a substantial epidemic of HIV/AIDS in older survivors of mother-to-child transmission is emerging in Southern Africa... [with] a failure to...adequately address the clinical needs of HIV-infected older children and adolescents” (Ferrand et al., 2009: 2039). While many NGOs, faith-based groups, and community-based organizations are working at the grassroots level to meet the needs of children affected by HIV/AIDS, few specifically address the needs of female OVC. A recent review of 14,343 documents with 414 judged relevant and reviewed on OVC found strong evidence was found that institutional care of OVCs should be the last resort (Franco et al., 2009).

Access to treatment is another programmatic gap for orphans living with HIV. A study in rural Uganda of 101 children living with HIV (56 girls and 45 boys), of whom 47 were orphans, highlighted the need to improve access to antiretrovirals for orphans. The study found that orphans were more likely to be at WHO clinical stage 4, suggesting that orphans are at a greater risk of progressing to AIDS than non-orphans and in need of timely treatment initiation (Ntanda et al., 2009). For children of parents living with HIV, theoretically adult treatment programs should also encourage HIV testing and counseling, followed by pediatric treatment, for children who test HIV-positive, but in practice, due to stigma, this is rarely done (Leeper et al., 2010). Yet even HIV-negative children are at increased risk of health problems if they live with sick parents at home (Kidman et al., 2010).

Recent guidelines by UNICEF on programming for vulnerable children that are HIV-sensitive are available, with some guidance on addressing the needs of girls (UNICEF, 2011).

A number of policy gaps exist regarding OVC (Engle, 2008). A review of National Plans of Action (NPA) for OVC found that “there is a wide range in the developmental appropriateness of the plans within the 17 countries. The most common interventions are health and nutrition and birth registration. Slightly less than half of the plans have components that include childcare centres (8) or community-based centre programmes (7). Some NPAs incorporated concerns for psychosocial support for younger children (4), a holistic approach to the treatment of HIV-infected children (6) and incorporating young children’s concerns into home-based care (3). Only two programmes mentioned capacity building for working with young children and three plans had age categories in their monitoring and evaluation plans. Some NPAs included programmes for young children but did not include funding” (Engle, 2008: v).

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Significantly, “WHO, UNAIDS and the international data sets are not gathered or coded by gender. This serious omission leads to ignorance by neglect – despite well established gender challenges in later life” (Sherr, 2008). Evaluations of OVC programs are just beginning. Chatterji et al. (2005) have noted that educational programs should target all out-of-school children, not only orphans. Adolescents ages 13–19 in particular need encouragement and support to stay in school. Program implementers need to develop proven and sustainable interventions to help improve the individual material well-being of children—both orphans and children with chronically ill caregivers. Policies should also ensure that national maternal and child health (MCH) programs focus attention on orphans. In particular, the primary caregivers of these children, some of whom are very young (15–24) or older (50+), need to be targeted by health promotion campaigns that typically reach mothers ages 25–49.

Despite the importance of early childhood development, “there is virtually no research on early childhood development interventions designed specifically for OVC or for high prevalence HIV settings” (AIDSTAR I, 2011: 1).

Some have suggested that it is important to look beyond survival oriented interventions for children affected by HIV to consider their rights, safety, access to health care, connections to family, and education and livelihoods by expanding PMTCT initiatives to include early childhood initiatives, but research needs to assess the value added of this synergy (Engle, 2012; Betancourt et al., 2010b).

Finally, there is debate between those advocating a focus on vulnerable children as a group, in order not to stigmatize those affected by HIV and those who argue that “with very limited resources in the developing world, it is difficult to know how we can reconcile the need to help this specific group of children with the need to avoid the stigma that may come with targeted interventions” (Cluver et al., 2012: 126). Although analysis of Demographic and Health Surveys and Multiple Indicator Cluster Surveys in 36 countries found that orphanhood and co-residence with a chronically ill or HIV-positive adult are not universally robust measures of child vulnerability as household wealth was a key factor (Akwaru et al., 2010). Targeting those who live in poverty needs to be a central criterion as well (Adato, 2012).

12B. What Works—*Care and Support: Orphans and Vulnerable Children*

1. Accelerating treatment access for adults with children can reduce the number of orphans, improve pediatric mortality and social well-being.
2. Educational support for orphan girls may reduce risk of HIV acquisition and increase educational attainment.
3. Programs that promote the strength of families and offer family-centered integrated economic, health and social support result in improved health and education outcomes for

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orphans.

4. Psychological counseling and mentoring for OVC may improve their psychological well-being.
5. Programs that provide community-wide cash transfers, microenterprise opportunities, old age pensions or other targeted financial and livelihood assistance can be effective in supporting orphans.

Promising Strategies:

6. Highly-active antiretroviral therapy (HAART) with good nutritional intake and regular medical care can improve health and survival of orphaned children living with HIV in resource-poor settings.
7. Providing community development projects, rather than a narrowly defined HIV/AIDS program, may reduce the stigma against OVC.

12B. Evidence

1. Accelerating treatment access for adults with children can reduce the number of orphans, improve pediatric mortality and social well-being. [See also *Treatment*]

- A prospective cohort study with 1,373 HIV-positive and 4,601 HIV-negative household members (over 70% respondents were women) conducted from 2001-2005 in **Uganda** showed that access to antiretroviral therapy (ART) and co-trimoxazole prophylaxis treatment program led to large reduction in mortality among HIV-positive adults living in resource-poor settings and in the rate of orphanhood. Compared with no intervention, ART and co-trimoxazole were associated with a 95% reduction in mortality in HIV-positive adult participants, an 81% reduction in mortality in their uninfected children younger than 10 years and a 93% estimated reduction in orphanhood. During the study periods households were visited every week by lay trained paid providers who resupplied medicine and monitored drug adherence, hospital admissions, potential symptoms of drug toxicity, death of a household member in the preceding 7 days, and orphanhood. No routine clinic visits were scheduled after enrollment and home-based care and services were provided, which greatly helped in overcoming the problem of inability of ART-eligible people to access routine health services due to poverty or poor transportation (Mermin et al., 2008). (Gray IIIa) (*treatment, mortality, orphans, Uganda*)
- The Joint Learning Initiative on Children and HIV/AIDS compiled over 50 systematic reviews by working groups of world OVC experts and found that “family-centred treatment programmes may accelerate the expansion of paediatric treatment, improve children’s adherence to therapy, and secure better outcomes for children living with HIV,” (Irwin et al., 2009: 21). JLICA cited a 2007 cohort study of 151 children in **South Africa** who were started on HAART, which determined that 89% of children had an adherence to treatment of greater than 95%, leading to 84% virologic suppression after 6 months and 80.3% suppression after a year. The study found that having at least one HIV-positive parent decreased the children’s chances of death, leading to the conclusion that treating parents and keeping families infected

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with HIV together can improve HIV outcomes (Reddi and Leeper, 2008). (Gray IIIb) (*orphans, treatment, South Africa*)

- A Joint Learning Initiative on Children and HIV/AIDS executed a systematic review of the impact of adult use of antiretroviral treatment on family well-being. The study evaluated primary research and modeling studies and found that “having parents on ART reduces the likelihood of children’s labour supply; increases children’s school attendance and improves their nutritional intake,” (Kimou et al., 2008: 9). Among 41 other studies, JLICA cited a 2004-2005 longitudinal household survey of 775 randomly chosen households, households with at least one known HIV-positive adult on ARV, and households with a known HIV-positive adult not receiving ARV in 100 villages in rural western **Kenya**. The study evaluated 482 children living in these households and determined that after treating adults with antiretroviral therapy for six months, the number of hours that the children in the household attend school increased by 20 percent overall, and 30 percent for boys. After six months of adult ART, the average hours a week worked by boys in the labor supply decreased by 7.46 hours. Lastly, ARV treatment of parents was found to improve the nourishment of young children (Zivin et al., 2007). (Gray IIIb) (*orphans, child labor, education, treatment, Kenya*)
- Among 3,646 mother-infant pairs in **Ukraine** followed between 2005 and 2009, receipt of antenatal antiretroviral prophylaxis was strongly associated with reduced risk of infant abandonment (Bailey et al., 2010). (Gray V) (*orphans, treatment, Ukraine*)

2. Educational support for orphan girls may reduce risk of HIV acquisition and increase educational attainment.

- A three-year longitudinal randomized control study was conducted in **Zimbabwe** in 2007 to determine if providing educational support to girls was effective to combat factors associated with increased HIV risk. In the intervention school, students received educational support in the form of fees, books, uniforms and other school supplies and additionally female teachers were selected to act as helpers in monitoring school absences. Retention rates were significantly higher in the intervention cohort; the control group was 6 more more likely to drop out of school and 3 times more likely to get married. Additionally, the intervention group participants were significantly less likely to be absent from school and to report that they delayed sexual debut. Girls in the intervention group were also more likely to endorse gender equality. In this study 10 high schools were selected and all orphan girls were invited to participate in the study, a total of 326 agreed to participate and were included in final analysis, with each primary school randomized to the intervention or control group. There were 184 girls in the intervention group with a mean age of 12.2 and 145 in the control group with a mean age of 12.3. Self-administered questionnaires were given to participants in order to collect demographic data and outcomes variables; the survey was conducted annually for three years. In addition, data regarding drop-out rate, absences, and enrollment rates were collected from the schools. Of all participants in the intervention group 8 students dropped out of school during the course of the study (4.5%) and 6 of them were married. Only two girls were known to be pregnant during the course of the study and both of them were in the control group. School support decreased HIV risk; in addition it provided numerous educational benefits to orphan girls. Although students were entitled to schooling regardless of ability to pay, fees were requested and children were chased away if they didn’t pay (Hallfors et al, 2011). (Gray II) (*education, OVC, Zimbabwe*)

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- A randomized trial with 105 orphans ages 12 to 14 years in **Kenya** found that provision of school fees, uniforms and a community visitor who monitored school attendance resulted in decreased school dropout and delayed sexual debut. All participating households received mosquito nets and blankets, and food supplements (Maize, oil, sugar) every two weeks for a cost of \$100 per year per child; 53 orphans received the intervention and 52 remained in the control group. The community visitor had 10 children in the experimental group on a monthly basis and also visited schools on a weekly basis to monitor attendance. The community visitor could buy sanitary napkins for girls during menses or arrange clinic visits for malaria or parasites. The budgeted cost to the intervention group was \$200 per year per child. After one year, those in the control group were significantly more likely to drop out of school (14% compared to 4%) and begin sexual intercourse (33% compared to 19%). Those in the experimental group were less likely to express acceptance of a beating if a wife refused sex and less acceptance of violence against women for any reason and increased acceptance of gender equity (Cho et al., 2011). (Gray II) (*education, OVC, Kenya*)
- A project that provides services through home based caregivers and a community center in **Zambia** resulted in a positive and statistically significant effect on school enrollment. In addition, participation in the program was associated with a 15.7 increased in appropriate age-for-grade for intervention children relative to control children. The study included two rounds of post-intervention data collection in 2003 and 2006 with 2,306 children aged 6 to 19 years interviewed in 2003 and 3,105 children aged 8 to 22 years of age interviewed in 2006. The OVC subsample included 2,922 children, with 1,242 of these exposed to the intervention. Children in the intervention group received services related to education, health, HIV prevention, psychosocial support and nutrition. The community school for the intervention group had meals, clinic services, HIV prevention education and psychological counseling. Also provided were school supplies, payment of government school feeds and food rations. “While this study suggests that [the intervention] Bwafwano is effective in improving schooling outcomes, it says nothing about whether it provides the best ‘bang for the buck’ relative to the alternatives” (Chatterji et al., 2010: 139). (Gray IIIb) (*education, OVC, Zambia*)

3. Programs that promote the strength of families and offer family-centered integrated economic, health and social support result in improved health and education outcomes for orphans.

- A study of 176 double AIDS orphans from 2006 to 2007 aged 8 to 18, from four AIDS orphanages in rural **China** found that children who had received family-based care reported the best scores on all psychological measures. Prior to being placed in AIDS orphanages, children has received family-based care by caregivers, including the surviving parent (38%), grandparents (22%) other relatives (19%) and non-relatives (22%). The children in the care of grandparents had the best scores on psychological measures. Depression was measured using the Center for Epidemiological Studies Depression Scale for Children; loneliness was measured using the Chinese version of the Children’s Loneliness Scale; and trauma symptoms were measured using a Chinese version of the Trauma Symptom Checklist for Children. There were 64.1% boys and 38.6% girls who had lived in the orphanage for an average of 21.17 months (Zhao et al., 2010b). (Gray IIIb) (*children, family, community-based care, China*)
- A study in **Kenya** with 766 caregivers and 1028 children found that support groups for caregivers was associated with better family functioning, and more positive feelings by caregivers toward children. For children whose caregivers were in support groups, these children exhibited fewer behavioral problems and reported lower incidence of abuse from adults in their household. Support for caregivers translated into positive effects both for

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caregivers and the children under their care, with outcomes holding after controlling for illness status and caregiver and child demographics (Thurman et al., 2012). (Gray IIIb) (*OVC, support groups, Kenya*)

- A study in **South Africa** measuring the effectiveness of a health education intervention designed to improve the skills and knowledge of elderly caregivers of orphaned and sick children as a result of HIV/AIDS, found that 141 participants who completed all sessions of the intervention, versus the 61 participants with incomplete or no participation at all, reported a more positive attitude towards people living with HIV/AIDS. Participants who were present at all sessions also reported an increase in their perceived ability to provide care for their dependents. The intervention consisted of four sessions, implemented over the course of four weeks. The sessions covered HIV/AIDS knowledge, effective intergenerational communication, home-based basic nursing care, accessing social services and grants, and relaxation techniques. A majority of the participants were female (81.7%) and participants were divided into groups of 10 to 12 each. Overall comparative effectiveness of the sessions between those who fully participated and those who partially or did not participate at all was measured at baseline, immediately following completion of all sessions, and three months after completion of all sessions. While the findings indicate a positive effect on assisting older caregivers in their care-giving responsibilities, no changes were found for caregiver's perceived ability to communicate with children and grandchildren (Boon et al., 2009). (Gray IV) (*children, grandparents, family, community-based care, South Africa*)
- Services that are “provided through integrated, family-centered delivery models” work best for children, according to the Joint Learning Initiative on Children and HIV/AIDS final report on children, AIDS and poverty (Irwin et al., 2009: 47). “Programmes obtain the best results for children when they adopt integrated intervention strategies providing a range of services to the whole family. The most effective delivery systems integrate HIV and AIDS services with family-centered primary health care and social services provided through community-based models,” (Irwin et al., 2009: 48). JLICA highlights **Rwanda's** National Policy and Strategic Plan for Orphans and Vulnerable Children, which looks beyond AIDS to provide a “minimum package of services” of healthcare, nutrition, formal education, livelihood training, protection, and psychological and socioeconomic support. The decentralized, rights-based system “can connect families to such opportunities through referral systems and linkages to public support or NGO programmes,” (Irwin et al., 2009: 49 citing Binagwaho et al., 2008). (Gray V) (*orphans, community-based care, Rwanda*)
- An orphan day care center in **Botswana** provides centralized care to over 355 orphans ages 2 to 18 with pre-school aged children cared for in a safe, supervised environment during the workday, relieving the caregiving burden for guardians and facilitating their ability to work or care for relatives with HIV. Older children come to the center after school to receive meals, participate in activities and receive counseling. The family outreach program delivers counseling to children's guardians during home visits. The center in Botswana has quality control measures in place to ensure that orphans benefit, but the labor-intensive efforts are more challenging to scale up (Kidman et al., 2007). (Gray V) (*orphans, counseling, Botswana*)
- A savings and loan program instituted for adolescent girl orphans in **Zimbabwe** found that adolescent girls were less likely to engage in transactional sex. One adolescent girl stated: “There was a temptation before to have sex for food, but now if I'm approached, I say I don't need it. Now I can pay for my own lunch.” (Miller et al., 2011a: 37). (Gray V) (*OVC, community care, sexual behavior, Zimbabwe*)

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4. Psychological counseling and mentoring for OVC may improve their psychological well-being.

- A cluster randomized control trial of a school-based peer-group support intervention with 326 AIDS orphans (aged 10-15) in Mbarara District, **Uganda** found that peer-group interventions when led by teachers and complemented by healthcare check-ups significantly decreased anxiety, depression and anger among the intervention group. Of the children, 42.6% were double orphans. The intervention provided twice-weekly peer-group support meetings conducted by a trained teacher over the course of ten weeks and supplemented these sessions with monthly healthcare examinations and treatment. The support meetings presented topics of concern to orphans through plays, poems, stories and games, asked the orphans to identify the problems embedded in the activities, inquired whether they had experienced similar issues, explored the causes of the problems and their effects on families, and brainstormed solutions. Although the children in the intervention group had started out having lower self-concept scores and higher indications of depression than the control group, the intervention group had lower scores of anxiety, depression, and anger at baseline (Kumakech et al., 2009). (Gray II) (*support groups, counseling, orphans, Uganda*)
- A 2006 follow up survey of an 18-month intervention with 593 youth household heads (equal number of males and females) aged 27 years and under, in **Rwanda** reported that a mentorship program may mitigate grief among youth. Youth with a mentor showed a decrease in marginalization, increase in perceptions of adult support and stability in grief levels. They also reported a slight though significant decrease in depressive symptoms. The mentoring program appears to have enhanced available support and overall community connectedness (Brown et al., 2009). (Gray IIIa) (*youth, depression, Rwanda*)
- A 2006-2007 post-test study of 6,127 children ages 8-14 in four OVC programs in **Kenya** and **Tanzania** found that kids' clubs had mixed results in improving children's psycho-social outcomes. One successful kids' club, which met once a month and had a standardized curriculum and an OVC supervisor on staff, was associated with higher perceptions of having adult support, improved pro-social behavior and fewer emotional problems (Nyangara et al., 2009a). (Gray IV) (*orphans, support groups, Kenya, Tanzania*)

5. Programs that provide community-wide cash transfers, microenterprise opportunities, old age pensions or other targeted financial and livelihood assistance can be effective in supporting orphans.

- A randomized clinic trial studied 268 adolescent orphans in their final year of primary school from fifteen comparable primary schools in Rakai District, **Uganda** and found that at ten months post-intervention, adolescents who had participated in an economic empowerment intervention had significantly better self-esteem and self-rated health measures than the control group. Girls reported greater increases in self-esteem than boys. Self-esteem was positively correlated with self-rated health functioning, and adolescents with increased self-esteem were found less likely to intend to engage in risky sexual behaviors. The SUUBI economic intervention focused on increasing assets for families and provided workshops on asset-building and planning, monthly meetings with mentors on life planning, and a Child Development Account (CDA) for each adolescent with a 2:1 match of contributions that could be used for "secondary education, vocational training and/or for a small family business" (Ssewamala et al., 2009: 193). The average monthly net deposit was \$6.33, which accumulated to \$228 per year, enough to cover almost two years of secondary education. The

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study participants had an average age of 13.7 years. The proportion of study participants who were paternal, maternal and double orphans was 41%, 19% and 40%, respectively (Ssewamala et al., 2009). (Gray II) (*adolescents, orphans, microfinance, self-perception, Uganda*)

- A 2005-2008 study in **Uganda** assessing the effect of economic assets on sexual risk-taking intentions among school going AIDS-orphaned adolescents, observed a significant reduction in sexual-risk taking intentions among 127 adolescents when enrolled in the SUUBI program – a combined microfinance youth empowerment and health-promotion approach targeting families raising AIDS-orphaned adolescents in Uganda. The study involved 260 AIDS-orphaned adolescents from 15 comparable schools, with 127 adolescents in the intervention group and 133 adolescents receiving standard of care. In addition to traditional care and support services, adolescents in the intervention group received 12 workshops on economic security and empowerment over the course of 10 months, with sessions on asset-building strategies and financial planning, a monthly mentorship program with peer mentors, and a child savings account. The child savings account served as an incentive to save, with a match rate of two to one, with a limit on the maximum savings that could be matched (US\$10 a month). Each child, with his or her primary caregiver as the cosigner, had access to the money in their own account, but not the matching funds. Participants could only access funds to purchase an asset after completing the 12 workshop sessions and all participants chose education as their saving goal. The children’s caregivers also valued education and most considered investment in small business development as a risk. Specific measures adapted from previously tested scales in the US, South Africa, and Uganda, assessed intentions to engage in sexual behaviors, individual socioeconomic characteristics, peer pressure, and parental or caregiver communication (Ssewamala et al., 2010). (Gray IV) (*adolescents, orphans, microfinance, sexual risk-taking, Uganda*)
- Old age pensions bring specific benefits to vulnerable children. The Joint Learning Initiative on Children and HIV/AIDS final report, which compiled over 50 systematic reviews by working groups of world OVC experts, found “that old age pensions help children ... households that include pension recipients increase spending related to children’s welfare,” particularly in the African policy context. JLICA cited a 2004 study that evaluated the impact of **South Africa’s** Old Age Pensions on children’s school attendance. When a household member received a pension, the children in the household attended school 20 to 25% more often. In the poorest quartile, old age pensions increased the chance that girls would attend school fulltime by 7% and for boys by 5% (Adato and Bassett, 2008 citing Samson et al., 2004).” (Gray IV) (*orphans, grandparents, pensions, South Africa*)
- A final report of a study on children, AIDS, and poverty, which compiled over 50 systematic reviews by working groups of world OVC experts, suggested “income transfers as ‘a leading edge’ intervention to rapidly improve outcomes for extremely vulnerable children and families,” (Irwin et al., 2009: 58). JLICA suggests unconditional income transfers and child poverty support grants for the African policy contexts. In particular, income transfers to women in the households improve children’s outcomes. The JLICA review of cash transfer programs cited a pilot income transfer study in **Malawi** and **Zambia** which found that in high HIV prevalence areas where families were targeted for the income transfer based on poverty, 70% of the participating families were affected by HIV (Adato and Bassett, 2008 citing Schubert et al., 2007). (Gray IV) (*orphans, financial assistance, Malawi, Zambia*)
- A community-based cash transfer program in **Kenya** that provided funds dispersed to local village development committing to strengthen their capacity to provide care and support to orphans found that communities implemented collectively diverse food- and income

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generating activities which benefited orphans. The program was implemented in 39 rural and subsistence farming communities and communities identified between 65 to 100 of the neediest orphans and their caregivers in each community. Each community received a cash transfer of 4000 Euros and project management committees, village development committees and the local district officer for social services prioritized activities. A total of 272 orphaned children, 30 caregivers and 80 village and project manager committee members were interviewed. Caregivers reported that the project had created unity and support among caregivers. One orphan girl stated: “This programme looks at the welfare of orphans by consulting the caregivers and orphans themselves about the problems affecting the community and supports them accordingly” (Orphan girl cited in Skovdal et al., 2010a: 5). A caregiver stated: “It has helped me to find hope of a brighter future for my grandchildren to become victorious and successful” (Caregiver cited in Skovdal et al., 2010a: 7). (Gray V) (*orphans, community care, Kenya*)

- A study with 1,400 adults in **South Africa** found that assistance to families as well as additional funds to support OVCs increased the likelihood of adults supporting orphans. When non-direct financial assistance such as paying for the child’s education and providing for a trained person to assist in care, were included, adults were more willing to care for orphans. However, 28% of best friends, 29% of strangers and 15% of fathers and 17% of grandparents said they would decline to take in a child or children if they were HIV-positive (Freeman and Nkomo, 2006). (Gray V) (*OVC, financial assistance, South Africa*)

Promising Strategies:

6. Highly-active antiretroviral therapy (HAART) with good nutritional intake and regular medical care can improve health and survival of orphaned children living with HIV in resource-poor settings.

- A study with 103 (61 male, 42 female, age range: 3-127 months) institutionalized HIV-infected orphaned children in **Tanzania** showed that after one year of being on HAART, children with severe malnutrition and declined CD4 values had significant increases in their CD4 counts. Their CD4 cell percentages increased from 10.3 to 25.3 percent and absolute count, from 310 to 660/mm³. Their nutritional status improved significantly. Two out of 27 untreated children became eligible for antiretroviral treatment. The study also showed that institutionalized children who do not meet the criteria for treatment can be safely monitored for immunological status with no mortality and no difference in clinical events compared to treated children in the short-term. HAART can be effectively used for HIV-positive children in resource poor settings along with good nutritional intake and regular medical care (Ble et al., 2007). (Gray IIIb) (*orphans, treatment, HAART, Tanzania*)
- A retrospective review in **Kenya** with 279 children (49% girls and 54% orphans) enrolled at nine HIV clinics between 2002 and 2005 and on antiretroviral therapy (ART) showed that ART for HIV-positive children produced significant and sustainable CD4 improvement and weight gains during the initial 30 weeks. The study found no effect of orphan status on ART adherence or rise in CD4 counts, at least in the short-term. The mean peak for CD4 percent increase at 30 weeks for orphans was 23% and that for non-orphans was 24%. The study indicates the feasibility of providing ART to children in resource poor settings (Nyandiko et al., 2006). (Gray IIIb) (*treatment, children, orphans, Kenya*)

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7. Providing community development projects, rather than a narrowly defined HIV/AIDS program, may reduce the stigma against OVC.

- A 2006-2007 study of 6,127 children ages 8-14 and 4,591 caregivers in four OVC programs in **Kenya** and **Tanzania** found that services targeting OVC or families affected by HIV/AIDS may also add to stigma. “A noticeable fraction of the sample across each study setting reported that there was community jealousy of services provided to OVC and their families.” Between 22 and 57 percent of the children across all study sites perceived jealousy for the services they received, while among caregivers these perceptions were higher – from 27 to 67 percent. “These results bear credence to both the importance of engaging the community in decisions regarding who will receive services, as well as programmatic efforts to sensitize the community on the needs of OVC and those of HIV-affected families,” (Nyangara et al., 2009a: 31). (Gray IV) (*OVC, stigma, Kenya, Tanzania*)
- A 2010 case study in **Tanzania** found that community-based initiatives to meet the needs of OVC are effective in improving their quality of life. Five months after opening, Goddfrey’s Children’s Centre housed 58 orphans, about one-third of all orphaned children in the community. Orphans were selected based on the severity of their need, with emphasis placed on accommodating double orphans (with neither mother nor father alive). Orphans received three meals a day and 90% attended the public school. The Centre provided after-school help with homework. It cost approximately US \$1700 per month to operate the Centre, or a daily cost per child of approximately US \$1. In 2005, Tanzanian and US researchers conducted an 18-month evaluation, examining the wellbeing of its children compared with other groups of children in the community. Centre orphans reported significantly fewer symptoms of depression than orphans living in the village with extended family members, and were significantly less depressed than children living with both parents. Centre orphans reported as many social supports as other groups of children in the community and did not report feelings of stigmatization or social isolation. School attendance, optimism towards shaping their future and overall health among Centre orphans was comparable to other children in the community. However, the Centre closed due to lack of sustainable options once US funding ended (Wallis et al., 2010). (Gray IV) (*OVC, community-based care, Tanzania*)

11B. Gaps in Programming—Orphans and Vulnerable Children

1. Interventions are needed to support women living with HIV to reduce infant abandonment.
2. Increased financial support is needed for adults, especially grandparents, caring for orphans, including for those who are HIV-positive.
3. Interventions are urgently needed to help girls enroll (and stay) in school.
4. HIV/AIDS programming should also reach young children.
5. Improved and timely access to antiretrovirals is needed for orphans.
6. Interventions are needed to assist parents dying of AIDS with planning for the future well-being of their children.
7. Further interventions to provide support programs, including counseling, are needed for AIDS-orphaned children to combat depression, social isolation and stigma.

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8. Further interventions are needed to help female OVCs reduce risky sexual behaviors and protect them from sexual violence.
9. Programs should encourage male involvement in children's treatment and orphan care.
10. NGO and government interventions must take care not to create dependence on externally funded services and decrease the community's sense of responsibility for OVC.
11. Interventions are needed for street youths who have high rates of HIV and intravenous drug use.

1. Interventions are needed to support women living with HIV to reduce infant abandonment. Studies found that families forced women living with HIV to abandon their infants; some due to erroneous fears that the infant could transmit HIV.

- Gap noted, for example, in **Ukraine** (Bailey et al., 2010; Pinkham and Shapoval, 2010), **Russia** (Zabina et al., 2009; Wolfe et al., 2010) and **Kyrgyzstan, Kazakhstan, and Tajikistan** (Shapoval and Pinkham, 2011).

2. Increased financial and other support is needed for adults, especially grandparents, caring for orphans, including those who are HIV-positive. Studies found families caring for orphans lacked adequate food and nutrition and reported financial difficulties in meeting basic needs.

- Gap noted, for example, in **Zimbabwe** (Skovdal et al., 2011a); **Uganda** (Nalwoga et al., 2010; Kintu et al., 2008); **Kenya** (Muga et al., 2009); and **Botswana** (Miller et al., 2006; Heymann et al., 2007b).

3. Interventions are urgently needed to help girls enroll (and stay) in school. *[See also Strengthening the Enabling Environment: Advancing Education]* Studies found that girls affected by HIV are more likely to be out of school, despite the protective factor of education in reducing the likelihood of HIV acquisition.

- Gap noted, for example, in a systematic review (Irwin et al., 2009); **Thailand** (Yoddumnern-Attig et al., 2004); **Tanzania** (Wobst and Amtdt, 2004); **South Africa** (Horizons et al., 2004); **Kenya** (HRW, 2003c).

4. HIV/AIDS programming should also reach young children. A review found that despite the impact of investing in early childhood interventions, few HIV/AIDS programs exist for young children.

- Gap noted, for example, in a systematic review (Irwin et al., 2009) and review of National Plans of Action for OVC (Engle, 2008).

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- 5. Improved and timely access to antiretrovirals is needed for orphans.** A study found that orphans were more likely to be at WHO clinical stage 4, and need timely treatment initiation.
- Gap noted, for example, in **Uganda** (Ntanda et al., 2009).
- 6. Interventions are needed to assist parents dying of AIDS with planning for the future well-being of their children.** [See also *Strengthening the Enabling Environment: Transforming Legal Norms to Empower Women, including Marriage, Inheritance and Property Rights*] Studies found that many parents dying from AIDS had not written wills nor provided custody arrangements for their children.
- Gap noted, for example, in **Kenya and Tanzania** (Nyangara et al., 2009a; Nyangara et al., 2009b), Hunter and Williamson, 2000).
- 7. Further interventions to provide support programs, including counseling, are needed for AIDS-orphaned children and their caregivers to combat depression, social isolation and stigma.** Studies found that AIDS orphans reported insufficient food, depression and stigma.
- Gap noted, for example, in **Cambodia, India, Kenya, Tanzania and Ethiopia** (Messer et al., 2010); **Haiti** (Surkan et al., 2010); **Zimbabwe** (Kembo, 2010; Nyamukapa et al., 2010); **Rwanda** (Betancourt et al., 2011); **Rwanda** (Thurman et al., 2008a); **South Africa** (Van der Heijden and Swartz, 2010; Cluver et al., 2007; Cluver and Gardner, 2007); **China** (Xu et al., 2010a and b; Zhao et al., 2010a; Zhang et al., 2009a; He and Ji, 2007).
- 8. Further interventions are needed to help female OVCs reduce risky sexual behaviors and protect them from sexual violence.** [See *Prevention for Young People*]
- Gap noted, for example in **South Africa** (Cluver et al., 2011).
- 9. Programs should encourage male involvement in children's treatment and orphan care.** A systematic review and several studies found that fathers are often overlooked in orphan care when the mother has died.
- Gap noted, for example, in a systematic review (Sherr, 2008); **South Africa** (Hill et al., 2008); and **Zimbabwe** (Nyamukapa and Gregson, 2005).
- 10. NGO and government interventions must take care not to create dependence on externally funded services and decrease the community's sense of responsibility for OVC.** An evaluation of programs providing services to orphans found that because of NGO interventions, communities believed they had no responsibilities towards caregivers and orphans.
- Gap noted, for example, in **Kenya and Tanzania** (Nyangara et al., 2009a).

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11. Interventions are needed for street youths who have high rates of HIV and intravenous drug use. A systematic, community-based, multicity assessment of street youth in Ukraine, of whom a quarter were girls, found high rates of HIV and low condom use and high rates of sharing needles, especially among orphans and who were injecting drug users.

- Gap noted, for example, in **Ukraine** (Robbins et al., 2010; Zapata et al., 2011).

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