



Joint Learning Initiative on Children and HIV/AIDS JLICA

Learning Group 1 – Strengthening Families

Co-Chairs: Linda Richter and Lorraine Sherr

CHILDREN THRIVE IN FAMILIES: FAMILY CENTERED MODELS OF CARE AND SUPPORT FOR ORPHANS AND OTHER VULNERABLE CHILDREN AFFECTED BY HIV AND AIDS

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*Angela Wakhweya¹
Rebecca Dirks¹
Kwaku Yeboah¹*

¹Family Health International, Prevention and Mitigation Division, USA

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The Joint Learning Initiative on Children and HIV/AIDS (JLICA) is an independent, interdisciplinary network of policy-makers, practitioners, community leaders, activists, researchers, and people living with HIV, working to improve the well-being of HIV-affected children, their families and communities.

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Preface - Learning Group 1: Strengthening Families

The work conducted in Learning Group 1 was based on the fact that families, in all their many forms, are everywhere the primary providers of protection, support and socialization of children and youth, and families exert a very strong influence on children's survival, health, adjustment and educational achievement. This influence tends to be greater under conditions of severe strain, such as is caused by HIV and AIDS, particularly in the context of poverty.

In general, functional families love, rear and protect children and buffer them from negative effects. Functional families are those that have sufficient material and social resources to care for children, the motivation to ensure that children are nurtured and protected, and are part of a community of people who provide one another with mutual assistance. Family environments are especially important for young children. It is well established that multiple risks affect the cognitive, motor and social-emotional development of children and that the quality of parenting, assisted by intervention when needed, can ameliorate such impacts.

From the start of the epidemic, families have absorbed, in better or worse ways, children and other dependents left vulnerable by AIDS-induced deaths, illness, household and livelihood changes, and migration. Similarly, families have contributed, more or less successfully, to the protection of young people from HIV infection. Under the devastating effects of the epidemic, families need to be strengthened – economically, socially and with improved access to services – to enable them to continue, and to improve, their protection and support of children and youth. Families that neglect and abuse children need to be identified and social welfare services must be provided to them.

Families, extended kin, clan and near community are the mainstay of children's protection in the face of the AIDS epidemic - as they have been in poor countries under other severely debilitating social conditions, including war, famine and natural disaster. Only a very small proportion of AIDS-affected children are currently reached by any assistance additional to support they receive from kith and kin. The most scalable

strategy for children is to strengthen the capacity of families to provide better care for more children.

The co-chairs, secretariat, lead authors and stakeholders of Learning Group 1 were guided in the work undertaken in the Learning Group by the following key questions. By and large, these are the critical research, policy and programme questions currently being debated in the field.

1. On which children and families should we focus?
2. What evidence is available on which children are vulnerable and what can be done to help them, and how good is the research?
3. What aspects of the HIV/AIDS epidemic impact on children, how and why?
4. How are families changing as a result of adult illness and death associated with HIV and AIDS?
5. In what ways are children's health, education and development affected by the HIV/AIDS epidemic?
6. What does knowledge and experience of other crises teach us about the AIDS response for children and families?
7. What can we learn from carefully evaluated family strengthening efforts in fields other than HIV and AIDS that can be usefully applied in hard hit countries in southern Africa?
8. What programmatic experience has been gained in strengthening families in the HIV/AIDS field?
9. What promising directions are there for the future and what do they suggest?
10. What mistakes have been made and what now needs to be done?

These questions form the structure of the integrated report. As indicated in the Preface, detailed data and references are to be found in the respective LG1 papers.

Twelve detailed review papers constitute the primary evidence base for the conclusions drawn and the recommendations made by Learning Group 1. The papers, their authors in alphabetical order, and their affiliations are listed below.

List of authors, affiliations and paper titles

Authors	Affiliation	Title
Adato, M Bassett, L	International Food Policy Research Institute (IFPRI) – United States of America	What is the potential of cash transfers to strengthen families affected by HIV and AIDS? A review of the evidence on impacts and key policy debates
Belsey, M	Consultant – United States of America	The family as the locus of action to protect and support children affected by or vulnerable to the effects of HIV/AIDS: A conundrum at many levels
Chandan, U Richter, L	Human Sciences Research Council (HSRC) – South Africa	Programmes to strengthen families: Reviewing the evidence from high income countries
Desmond, C	Human Sciences Research Council (HSRC) – South Africa	The costs of inaction
Drimie, S Casale, M	International Food Policy Research Institute (IFPRI), Regional Network on AIDS, Food Security and Livelihoods (RENEWAL), Health Economics and AIDS Research Division (HEARD – South Africa	Families' efforts to secure the future of their children in the context of multiple stresses, including HIV and AIDS

Haour-Knipe, M	Consultant – Switzerland	Dreams and disappointments: Migration and families in the context of HIV and AIDS
Hosegood, V	London School of Hygiene and Tropical Medicine (LSHTM), Human Sciences Research Council (HSRC) – South Africa	Demographic evidence of family and household changes in response to the effects of HIV/AIDS in southern Africa: Implications for efforts to strengthen families
Kimou, J Kouakou, C Assi, P	Ivorian Centre for Economic and Social Research (CIRES), Family Health International (FHI) - Côte d'Ivoire	A review of the socioeconomic impact of antiretroviral therapy on family wellbeing
Madhavan, S DeRose, L	University of Maryland – United States of America	Families and crisis in the developing world: Implications for responding to children affected by HIV/AIDS
Mathambo, V Gibbs, A	Human Sciences Research Council (HSRC) – South Africa	Qualitative accounts of family and household changes in response to the effects of HIV and AIDS: A review with pointers to action
Sherr, L	Royal Free and University College Medical School – United Kingdom	Strengthening families through HIV/AIDS prevention, treatment, care and support
Wakhweya, A Dirks, R Yeboah, K	Family Health International (FHI) – United States of America	Children thrive in families: Family-centred models of care and support for orphans and other vulnerable children affected by HIV and AIDS

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List of Acronyms

ADRA	Adventist Development and Relief Agency
AIDS	Acquired immune deficiency virus
CBO	Community based organization
CCF	Christian Children's Fund
CCIH	Christian Connections in International Health
FAO	Food and Agricultural Organization
FBO	Faith based organization
FHI	Family Health International
GAPA	Grandmothers Against Poverty and AIDS
HIV	Human immunodeficiency virus
JLICA	Joint Learning Initiative on Children and AIDS
LG1	Learning group 1
LG2	Learning group 2
NGO	Non governmental organization
NMCF	Nelson Mandela's Children's Fund
OVC	Orphans and vulnerable children
SACBC	South African Catholic Bishop's Conference
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
WFP	World Food Programme
WHO	World Health Organization
WVI	World Vision International

1. Introduction

AIDS has been and continues to be the leading cause of adult mortality worldwide, with an enormously disproportionate impact on Sub-Saharan Africa (Foster et al, 1996; Foster & Williamson, 2000; Monasch & Boerma, 2004; UNAIDS & WHO, 2007). Over 68% of adults and nearly 90% of children infected with HIV live in this region. In 2007 an estimated 2.1 million people died due to AIDS, 76% of which occurred in sub-Saharan Africa. Moreover, over two-thirds of the 2.5 million new HIV infections in 2007 occurred in sub-Saharan Africa. Unique to this region, women make up the majority (61%) of people living with HIV (UNAIDS & WHO, 2007). Southern Africa has been most heavily impacted by the epidemic, with South Africa as the country with the largest number of HIV infections in the world. In fact, southern Africa accounts for 35% of all people living with HIV and 32% of all new HIV infections and AIDS deaths globally in 2007 (UNAIDS & WHO, 2007).

Due to the disproportionate impact of HIV/AIDS on Sub-Saharan Africa, the vulnerability of children in this region is particularly acute and has increased exponentially since the advent of the HIV epidemic. Orphaning is not expected to decrease in most countries in sub-Saharan Africa (UNICEF et al, 2004; UNAIDS & WHO, 2007). Alarming, those countries on the southern most tip of Africa with the highest HIV prevalence levels are now experiencing a significant shift in the burden of orphan care from surviving parents to predominantly older females, particularly grandmothers (Monasch & Boerma, 2004; Wiegers et al, 2006). Increased vulnerability and orphaning will continue to rise as HIV-positive parents become ill and die from AIDS (UNICEF, USAID & UNAIDS, 2004). HIV/AIDS impacts children in nearly every aspect of lives. The potential impact on children includes loss of family and identity, loss of assets and their inheritance, depression, homelessness, migration, decline in health status and health care, declining nutritional status, increase demands on them for labor and caregiving, and loss of educational opportunities (Richter, Manegold & Pather, 2004; Belsey, 2005) .

Currently, families and communities provide the majority of the care and support to children affected by HIV/AIDS (Foster, 2006). The vast majority of families and communities trying to care for affected children do not receive adequate external

assistance (UNICEF, USAID & UNAIDS, 2004). Civil society also shoulders a significant burden in action on behalf of children affected by HIV/AIDS. However, governments have the overarching responsibility to support families and communities by delivering quality public services, particularly in the health, education and social welfare sectors. Governments should provide children with a minimum standard of living in cases where parents and caregivers are unable to do so. Moreover, governments must be committed to the development and implementation of national policy and guidelines for orphans and other vulnerable children given the burden of orphaning that will continue for some time to come (Webb et al, 2006; Monasch & Boerma, 2007).

In many countries, families living with, affected by and made vulnerable to HIV/AIDS have been advocating for the need to strengthen families and support communities in caring for children living in the context of HIV/AIDS. The literature is unequivocal in finding that despite the enormous strain that HIV/AIDS has placed on families, particularly in sub-Saharan Africa, families continue to absorb orphans, but are in urgent need of greater external support (Haddad and Gillespie, 2001; Bray, 2003; Richter, Manegold & Pather, 2004; Wiegers et al, 2006; Monasch & Boerma, 2004). Global partners and international implementing agencies have endorsed the *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* (UNAIDS et al, 2004). Despite this commitment, implementing agencies continue to grapple with how to translate these global and national strategies into actual practice, and to define exactly what a family centered approach means in practice (FHI interview, 2007). Working at the frontlines of the epidemic, community and faith-based organizations (CBOs/FBOs) have played a critical role in supporting affected children and their families globally (Richter, Foster & Sherr, 2006). To date, there have been few systematic efforts to document experiences and lessons learned in family centered approaches, and explore how implementing agencies and governments can collaborate to strengthen families (FHI interview, 2007; Plan USA Key Informant Interview, 2007).

2. Background

The majority of orphans in sub-Saharan Africa today are due to HIV/AIDS, most of whom are paternal orphans (Monasch & Boerma, 2004; UNICEF, 2006), Numerous

census data, DHS and situation analyses, have indicated that the majority of orphaned children are living with a female household head, usually widowed, and most often their surviving mother (UNICEF, USAID & UNAIDS 2004; Sarker, Neckermann, & Müller, 2005; Howard et al, 2006; Heymann et al, 2007; Oleke, Blystad & Rekdal, 2005). What is also often not mentioned in the litany of statistics about orphans in sub-Saharan Africa is the fact that the majority of children living in Africa today are *not* orphaned and for a majority of orphaned children, at least one of their parents *is* alive, usually the mother (Monasch & Boerma, 2004). There is hope *and* a chance to hold this pattern, if the onslaught of HIV/AIDS on families in sub-Saharan Africa is arrested. However, most photographs, videos and appeals show children alone, in rags and in the presence of a foreign aid worker rather than with their surviving parent whose survival is most important to the children.

Research has demonstrated that children are better able to cope with their vulnerabilities when their adult caregiver is healthy and able to provide love and cognitive stimulation (Richter, Foster & Sherr 2006). If a child has a biological relationship with their adult caregiver or head of household, their health, educational and nutritional outcomes fare better (Adato et al, 2005; Verhoef & Morelli, 2007). This is sometimes referred to as Hamilton's Rule where the greater the biological relationship of the child to an adult caregiver or head of household, the better their health, educational and nutritional status (Case, Paxson & Ableidinger, 2004). The health, well-being and survival of the mother is critically important for particularly young children under the age of 6 years, critically so for infants below the age of 1 year and highly influential for adolescent children, particularly girl teenagers. In Zimbabwe teenage girls who were maternal orphans were found to have relatively lower education levels and poorer reproductive health outcomes - including heightened risks of HIV (Gregson et al, 2005). The socioeconomic status and infrastructure of the community in which children live is also important. However, the care and support of an adult caregiver, particularly by one or (better still) both parents, has an overriding influence on children's well-being and survival (UNICEF et al, 2004). The health of female caregivers particularly (mothers, grandmothers, older sisters, and aunts) has been shown to have a significant impact on household welfare indicators. The deaths of adult women heighten food insecurity within their households, decrease opportunities for children to attend school, increase the burden of work upon remaining

household members, and increase household poverty (Case, Paxson & Ableidinger, 2004).

Since HIV/AIDS has such a significant impact on the morbidity and mortality of adult members of households who are crucial to the survival and well-being of children, interventions that focus on orphans and other children made vulnerable by HIV/AIDS should also assess the needs of their surviving parents and/or other adult caregivers. Ideally, program interventions for children affected by HIV/AIDS should be designed to link the entire family (adults and children) to comprehensive packages of services provided by the government, NGOs, FBOs, CBOs, and the private sector (UNICEF et al, 2004). Essential to such a family-centered approach is the understanding that individual children and their families have different needs, which change over time. It is also recognized that pervasive poverty, coupled with limited internal and external resources available to the community, dictate that programs carefully balance between emergency and long-term solutions and are mindful of the importance of investing in long-term solutions such as working over time with families specifically and communities more generally. A factor crucial to the effectiveness of a family-centered model of care is the ability to reach all members of the family, including fathers. In some communities men are less likely to seek external support and participate in Orphans and Vulnerable Children programmes (Dlamini, 2004). Strategies designed to increase participation and uptake of services should include an approach targeted at fathers and other male caregivers.

3. Objective

This paper will summarize the global evidence that we were able to access from the formal and informal literature related to family-centered models of support to children affected by HIV/AIDS, within the time and budgetary limitations of this study. It will also collate the views and perspectives of respondents from selected implementing agencies about family-centered approaches to care for vulnerable children, and how they integrate such an approach into the design of their programs that focus on orphans and other vulnerable children. The evidence presented in this paper aims to provide guidance to national level policy makers and program planners within implementing agencies on

the opportunities and challenges of family-centered approaches to supporting children affected by HIV/AIDS.

14. Key Conceptual Definitions used in this Paper

Orphan

An orphan is a child under 18 years of age whose mother, father or both parents have died due to any cause. A paternal orphan is a child whose father has died, and a maternal orphan is one whose mother has died. A single orphan is a child who has lost one parent, and a double orphan is a child who has lost both parents (UNICEF et al, 2004).

Vulnerable child

The definition of child vulnerability is often modified according to the political, legal, cultural, and economic contexts in a particular setting, and is therefore very context specific. Community definitions of a vulnerable child may also differ from those used by government agencies, such as in National OVC and/or Child Policy Frameworks (Skinner et al, 2006). Locally-derived understandings of vulnerability must be taken into consideration when planning and implementing orphans and other vulnerable children programmes in order to reduce inclusion and exclusion-based discrimination (Webb et al, 2006). In this paper, we define children as vulnerable when they are under 18 years of age and are separated from their parent and/or adult caregiver, are malnourished, abused, neglected, out of school, disabled, physically or mentally ill, required to do excessive work, or lack access to basic services (adapted from Richter, Foster & Sherr, 2006).

Family

A family is defined as a group of two or more persons related by birth, marriage, or adoption and residing together (adapted from US Census Bureau, 2003). This definition is context and culturally relative in that communities may recognize a different meaning of “family” that may include not only members of the immediate family who reside together but members of the extended family who may live in adjacent or distant homes.

Household

A household includes all the persons who occupy a housing unit. Households are subdivided into family households and non-family households. The occupants may be a single family of related persons, one person living alone, two or more families living together, or any other group of related or unrelated persons who share living arrangements (US Census Bureau, 2003). This definition is relative, in that communities may recognize a different meaning of “household” based on the local context.

Family-centered care

Family-centered care is based on a bio-psychosocial systems approach where the primary focus of healthcare is the client in the context of their family; and, the client, family, and clinician are partners in healthcare (McDaniel et al, 2005).

Comprehensive Care

Comprehensive care refers to the concurrent prevention and management of multiple physical and emotional health problems of a patient over a period of time in relationship to their family, life events and environment (American Academy of Family Physicians, 2007).

In the context of this paper, comprehensive care for families made vulnerable by HIV/AIDS refers to a range of quality healthcare and social support services for children and adults affected by HIV and AIDS that may range from primary health care (preventive and curative); HIV/AIDS prevention, care and treatment; food security and nutrition; formal education and vocational training support; legal support; child protection services; shelter support; household socioeconomic strengthening (includes cash transfers and livelihood support); psychosocial support; and, spiritual support.

Coordinated care

In the context of this paper, coordinated care is a system of service programs and/or service providers that are linked through a referral network(s) that is (are) (preferably) formalized or non-formalized and in which referrals made and referrals completed can be tracked and evaluated in a cost effective manner through efficient communication channels (Family Health International internal discussions, 2007)

Family-centered approach

In the context of this paper, family-centered approach is defined as a comprehensive, coordinated care approach that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs, either directly or indirectly through strategic partnerships and/or linkages and referrals with other service providers.

5. Methodology

A three-pronged methodology was used to identify all relevant documentation and programs: 1) a global literature search of peer-reviewed articles published in English; 2) a web-based search of other literature published in English on the subject, to include reviews and evaluations of orphan and other vulnerable children programs; and 3) interviews with key respondents from selected implementing agencies supporting programs that seek to support orphans and other vulnerable children in sub-Saharan Africa. Interviews were conducted by phone and email using a two-page questionnaire designed by the authors. The questionnaire was distributed through two OVC-related listservs ~ the OVC Task Force and OVC Working Group of Christian Connections in International Health (CCIH).

Global Literature Search of Peer-Reviewed Articles

Peer-reviewed articles were identified through a global literature search of major databases of peer-reviewed articles published in English. This search was conducted using key academic search engines such as FirstSearch, ProQuest, Social Science Index, and PubMed. The databases were searched strategically, using search terms that include “family-centered programs” combined with “orphans”, “OVC”, “vulnerable children”, “children”, “care”, “support”, “treatment”, “HIV prevention”, “HIV”, “AIDS” and “HIV/AIDS”.

Web-Based Search of Other Literature

Non-peer-reviewed literature or “gray” literature was identified through a search of the web utilizing Google®. Gray literature included descriptive pieces on past or present programs that provide care and support to orphans and other vulnerable children, evaluation reports of those programs; and general handbooks, guidelines, and

frameworks of models of care and support to children affected by HIV. This literature was then reviewed for any discussion or description of “family-centered” approach, strategy, model, program, care or treatment.

Interviews with Key Respondents

A short three-page key informant questionnaire was designed (see Appendix). The questionnaire was designed to elicit information from technical officers, specialists, advisors and program managers working for major international implementing agencies and national/local organizations working in the area of orphans and other vulnerable children care and support. It was circulated through two OVC listservs: the OVC taskforce listserv and the OVC working group of Christian Connections in International Health listserv. Respondents either completed the questionnaire and returning it by email or were interviewed by phone. Respondents were technical and program staff from either headquarters or in the field who were informed of the rationale and objectives of this review and then asked to describe their Orphans and Vulnerable Children program according to six domain areas as identified as key to a family-centered approach.

6. Analytic Approach

When analyzing the global literature of peer-reviewed articles, the gray (or non-peer-reviewed) literature, and the information gleaned from the key respondents, we searched for descriptions of family centered approaches in the care and support of children made vulnerable by HIV/AIDS. We analyzed ways in which any programs described are utilizing the first major global principle signed on by major actors in the HIV/AIDS arena and encapsulated in the *Framework for the Care, Protection and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS* and *Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action*. The analysis of the literature and the information from the key informant questionnaires was divided into the following seven domain areas that were considered essential to a family-centered approach¹:

- A definition for family centered care, a strategy of family centered care, or model of a family centered approach to the care and support of orphans and other vulnerable children made vulnerable by HIV/AIDS.

- Strengthening the capacity of families to protect and care for orphans and other vulnerable children made vulnerable by HIV/AIDS by:
 - (a) Prolonging the lives of surviving parents and/or other adult caregiver(s) by providing them with/linking them to/facilitating their access to essential primary health care;
 - (b) Providing HIV/AIDS related health care (prevention, care and treatment) for the adults and children in the family directly;
 - (c) Providing primary health care for the adults and children in the family directly;
 - (d) Providing household economic strengthening support to adults in the family;
 - (e) Providing educational and other essential support to children in order to relieve the economic strain on the household;
 - (f) Providing access to vocational training or other skills acquisition in order to improve employment opportunities of adults and older children in the household;
 - (g) Providing psychosocial support to the adults and children in the family in order to minimize depression and anxiety;
 - (h) Providing spiritual support to the adults and children in the family to support their religious belief structures that promote hope;
 - (i) Providing food security and nutrition support to the adults and children in the family;
 - (j) Providing shelter support to the family;
 - (k) Providing shelter support to vulnerable children or children without adult care in as family-like structure as possible;
 - (l) Providing legal support for the protection of the rights of the adults and children in the family, including the protection of their assets; and
 - (m) Providing child protection support that allows families to remain intact without putting any child at risk of harm.

- Partnershipsⁱⁱ with key service providers i.e. governmental, non-governmentalⁱⁱⁱ and private sector to provide comprehensive services to adults and children affected by HIV/AIDS in the families being served.
- Leveraging^{iv} the provision of services and resources by other key service providers i.e. governmental, non-governmental and private sector, to cater for the comprehensive needs of entire families made vulnerable by HIV/AIDS.
- Referral networks and linkages that exist or are strengthened and include community volunteers, staff and other health and social workers who can monitor the capacity of families affected by HIV/AIDS to cope and the children within them to grow and thrive.
- Regular monitoring of children at a child outcome level according to specific domain areas^v to assess whether they are thriving under the care of a surviving parent or other adult caregiver.
- Community capacity-building and sustainability, i.e. building technical and programmatic capacity through training and technical assistance; working with local individuals, organizations, institutions and structures; provided resources (people, currency, commodities, structures) to continue to deliver quality services; or using another mechanism of sustainability.

7. Results

The literature search of peer-reviewed journal articles using Social Science Index, First Search, ProQuest, and PubMed resulted in 127 articles. Social Science Index resulted in 67 articles, First Search resulted in 23 articles; ProQuest resulted in 10 articles; and PubMed resulted in 27 articles. After removing duplicate articles, 52 articles were identified and analyzed for the literature review. Additionally, six pieces of relevant gray literature from the web were identified utilizing Google[®].

Lastly, seventeen key informant interviews were conducted among US implementing agencies and South African implementing partners. Respondents from four organizations completed the questionnaires circulated through the list-servs and included headquarters and field based personnel (International HIV/AIDS Alliance, Ukimwi Orphans Assistance, World Vision International, International Cooperation

Cambodia). Respondents from thirteen organizations completed the questionnaire through a phone interview (Christian Children's Fund, Plan USA, Starfish Greathearts Foundation, Nelson Mandela Children's Fund, Family Health International, World Vision International, Thabang Children's Project, Grandmother's Against Poverty and AIDS, AIDS Foundation of South Africa, Ingwavuma Orphan Care, and National Association of Child Care Workers).

Identification of family centered approaches/models

We found a dearth of literature and respondents who either defined family centered care, a strategy for family centered care or offered a model of a family centered approach. Many articles, reports and respondents indicated a familiarity with the *Framework* document and all five strategies described therein i.e. strengthening families, supporting communities, increasing access to essential services, supporting governments to articulate policies and legislative frameworks; and, creating an enabling environment that is free of stigma and discrimination. However, families and "family centered approaches" were often equated to communities and community level interventions and in some cases an assumption that "family" is a Western concept and not common in Africa given the reliance on the extended family or "community." Furthermore, the findings from this gray literature search and review of these documents reveal an attempt by many national NGOs and CBOs working at the grassroots level who have not documented their experiences in the formal peer reviewed literature but are making significant attempts at family centered approaches to the care and support of orphans. The general trend from the responses to the questionnaire and through discussions with the respondents revealed that the majority of implementing agencies do not have a working definition of a "family centered approach" nor do they subscribe to any set of activities that they would or could broadly package as family centered.

Strengthening the capacity of families

In the literature, there were a few descriptions of various mechanisms through which a comprehensive program can strengthen the capacity of families to protect and care for orphans and other vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support (such as education, food security and

nutrition, health care, shelter, legal support, child protection and/or spiritual support) according to assessed need and capacity. Four programs were described in Dlamini 2004 of the Kellogg Foundation OVC Program in Botswana (Botswana Christian Intervention Programme) and South Africa (The Morning Star Children's Centre; Seratuwa Thembi Development Agency; and, St Kizito's Children Programme). The Kellogg OVC program in South Africa that was described appeared more diverse including activities such as food security and nutrition activities, income generation for older youth and adult caregivers, psychosocial support activities for adults and children. However, despite heroic attempts at supporting families, many of these organizations are struggling for revenues to scale up their activities. In Botswana, for example, 47% of orphan caregivers reported financial difficulty and 18% were unable to meet basic needs (Heymann et al, 2007). Additionally, a study in South Africa demonstrated that most prospective caregivers would require assistance, financial and otherwise, in order to take in additional children (Freeman & Nkomo, 2006). In addition, there needs to be more sustainable and broader scale efforts to increase economic opportunities for older youth, women and communities.

Several articles also determined that for families to provide proper care to orphans and other vulnerable children, there is a need for wider sectoral responses such as universal access to primary and secondary education as well as primary health care for women and children (Wakhweya et al, 2002; Deininger, Garcia &Subbarao, 2003; Case, Paxson & Ableidinger, 2004).

The key informant interviews, however, revealed considerable efforts are being made to provide comprehensive services using a family-centered approach. Often times, the approach is labeled as a community-based approach. For example, the Thabang Children's Project, a small NGO located in Limpopo, South Africa, provides various services that strengthen the ability of families to care for children (Thabang interview, 2008). The organization links children and caregivers to primary health care and HIV/AIDS services, assists families with applying for social assistance grants, provides educational support to children, provides vocational support to older children, links children and families to psychosocial support, provides nutritional support, and provides child protection services while working to allow families to stay intact. These services are essential components of a family-centered model.

Partnerships

Partnering through a grant, agreement, memorandum of understanding or informal verbal agreement can be an essential step that allows different sectoral actors to come together to provide services together to a vulnerable population. In the literature there were several programs that described the provision of services in partnership with government, non-government and/or the private sector (Beard, 2005; Dlamini, 2004; O'Hare et al, 2005; Shishana et al, 2006; Kidman, Petrow, & Heymann, 2007).

Similarly, this approach was found to be common in each of the key respondent interviews of the implementing organizations. For example, the Nelson Mandela Children's Fund strongly encourages its grant recipients to form partnerships with service providers, especially with local health departments (NMCF interview, 2008). Likewise, the Starfish Greathearts Foundation requires that the community-based organizations (CBOs) it funds form formal or informal partnerships with local, provincial, and national government service providers (Starfish interview, 2008). The types of partnerships vary by CBO.

Leveraging services/resources by other sector actors

Leveraging the provision of services or resources by other sector actors in government, non-governmental and the private sector is another strategic mechanism through which a service provider can increase or improve services to the vulnerable through a formal written or informal verbal agreement. Examples of leveraging were rare but included some innovative examples in the literature (Dlamini, 2004; Kidman, Petrow, & Heymann, 2007). For example, Mahalapye Orphan Care in Botswana leveraged funding from the Social Welfare Department, local banks and business community, political leaders, and other international organizations in order to provide services to orphans and their families (Dlamini, 2004).

Again, this was a common strategy used among the implementing organizations interviewed. For instance, the Thabang Children's Project described how it leveraged resources from the health department to pay for home-based care workers, administration costs, stationary, and other miscellaneous office supplies (Thabang

interview, 2008). The Nelson Mandela's Children Fund explained that resources are often leveraged from churches for care and support, as well as the private sector; however it can be a struggle to convince local government that they have a responsibility to provide resources (NMCF interview, 2008).

Referral networks

Referral Networks may either be formal or informal and are increasingly becoming necessary due to the multi-sectoral needs of vulnerable children and the adults within their family and the inability of any one provider to cater for the needs of the entire family on their own. There were multiple examples of both formal and informal networks in the literature (Beard, 2005; Dlamini, 2004; O'Hare et al, 2005; Kidman, Petrow, & Heymann, 2007) as well as among the key informants from nearly all the implementing agencies interviewed.

While existence of referral networks was common, the strength of those networks varied. While Thabang Children's Project described a formal referral system with the local health department - in order to track antiretroviral treatment defaulters (Thabang interview, 2008), the majority of referral systems were described as informal. In the area where the Christian Children's Fund works, referral networks are typically these are weak and so are primarily informal (CCF interview, 2008); the respondent interviews from the majority of organizations also described referrals as typically being informal (Plan USA interview, 2008; Ingwavuma interview, 2008; World Vision interview, 2008; International Cooperation Cambodia interview, 2008; Starfish interview, 2008).

Monitoring child outcomes

Monitoring child outcomes at the family level including the status of the adults as an indicator of the status of the child is key in any kind of family-centered model. Many programs found in the literature described the use of a regular monitor of children and/or households they lived in including social workers, community volunteers and teachers (Dlamini, 2004; O'Hare et al, 2005; Shishana et al, 2006; Kidman, Petrow, & Heymann, 2007). While key respondents were not specifically questioned regarding their use of standard monitoring tools, the majority of organizations interviewed stated

that regular child monitoring was taking place. Several, however, expressed a need for strengthening child monitoring (Plan USA interview, 2008; GAPA interview, 2008; IHAA interview, 2008; Thabang interview, 2008).

Capacity-building and sustainability

Sustainability of family-centered models needs to be examined carefully given the potential cost to a program that is conceivably seeking to reach more people in a family than children alone. Moreover, the comprehensiveness of the approach requires some coordination of care that would have to be facilitated by an entity, preferably a governmental institution such as a Ministry of Social Welfare/Development that has the mandate to cater for the needs of vulnerable populations or a local civil society organization that has strong links to the responsible governmental institution.

Though discussion of sustainability was limited in the literature, many key informants described an attempt to integrate plans for sustainability of the program and build capacity of the community from the outset. The AIDS Foundation of South Africa described partnerships with the community as a key strategy to supporting sustainability (AIDS Foundation of ZA interview, 2008); partnerships are formed with the community and other stakeholders, local authorities, and traditional leaders to ensure that orphans and other vulnerable children will not be left without any support. Starfish Greathearts Foundation offers an 18-month training and mentoring program to CBOs, which is designed to build capacity and self-sustainability of the CBOs (Starfish interview, 2008). Care workers receive training in managing funds, accounting, reporting, fundraising, and good governance. After 18 months, CBOs “graduate” and are put into an independent category, where they may receive some additional assistance and support (to a lesser degree).

It must be noted that the organizations also acknowledged difficulties in describing sustainability in the context of a long term disease like HIV/AIDS which will require a lengthy engagement and investment in a community. Nonetheless, this paper attempts to define sustainability for family centered programs that seek to provide care and support for vulnerable children and adults (see Policy Implications below).

8. Discussion

Overall, the global literature review revealed little information directly relating to a family centered model and support for orphans and other vulnerable children. On the other hand, information gleaned from key informant interviews revealed that while the term “family-centered” is rarely used, an attempt is being made to offer services using a family-centered approach. Taken collectively, the literature and interviews offer several considerations.

First, there were very few clear definitions of family centered approaches or family centered interventions. It was evident that while the literature and implementing organizations are familiar with the five strategies embodied in the Framework document, there is a struggle to turn this strategy into action or into clear interventions whose outcomes and impact can be assessed at the family level (Beard, 2005, Key Informant Interviews, 2007/8; Shishana et al, 2006). One program by Family Health International, Nuru Ya Jamii in Nakuru, Kenya, sought to implement a model of a child focused, family centered and community based approach (FHI interview, 2007). The Nuru Ya Jamii program represented an attempt to convert the family centered strategy in the Framework into an actual program at the community level.

This paper also offers a working definition of family centered approach for implementing organizations to incorporate into their program designs for orphans and other vulnerable children as being a comprehensive, coordinated care approach that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs, either directly or indirectly through strategic partnerships and/or linkages and referrals with other service providers. Family centered interventions are defined across a continuum that include the following for adults and children: primary health care; HIV/AIDS specific prevention, care and treatment; educational support for children as a means of household economic relief; food security and nutrition; shelter support; psychosocial counseling and support; spiritual support as appropriate; child protection, particularly from abuse and neglect, but under the care of a caring adult; household economic strengthening; legal support.

There is widespread assumption that families are disintegrating or have completely disintegrated rather than a nuanced discussion of families along a continuum of “rupturing, transient, adaptive, and capable.” (Abede & Aase, 2007). Many authors and implementing agencies argued that there should be a greater focus on the agency and resilience of families that needs to be elucidated. Interventions need to be tailored to strengthen the intrinsic agency and resilience of the family, especially related to preventing the death of surviving parents, and improving the health of adult caregivers in the extended family - particularly grandparents (grandmothers more specifically) - under whom many children thrive and grow; improving the livelihood of families over the long term after short term interventions such as cash transfers and food aid; and, household economic strengthening activities that would assist in improving the capacity of families.

The majority of orphans are paternal orphans and many still reside with the surviving mother. In areas where the HIV epidemic has matured, many children have lost their mother as well, in which case the majority are living with the grandmother (Heymann et al, 2007). This review illustrated that many fathers are not taking on the caregiving responsibility of orphans and instead the majority of caregivers are single widowed female heads of households, in other words, the surviving mother, the grandmother or aunt (Monasch & Boerma, 2004; Watts et al, 2005; Sarker et al, 2005). There are very few child headed households, often headed by an older sibling, and can be transient when they end in absorption by the extended family (Thurman et al, 2006). The disintegration of households as a result of double orphaning, sibling dispersion and migration of remaining children in search of other adult caregivers or income generation is a growing phenomenon that needs to be monitored carefully and interventions designed to place children under the care of an adult caregiver, not institutions or orphanages, who is supported to meet the needs of the new members of their household. (Wiegers et al, 2006; Richter, Manegold & Pather, 2004; Wolff & Fesseha, 2005; Smyke et al, 2007).

Currently women comprise the majority of people living with HIV/AIDS in sub-Saharan Africa. Children survive better with mothers (Pavard et al, 2005; Anderson et al, 2007), and as it is often mothers who are the surviving parent, there is a window of opportunity to keep them alive to care and nurture their children. For children whose mothers have

died, particularly those whose mothers have died first, fathers need to be counseled and supported in taking on the caregiving responsibility and there are some successes in this vein (Dlamini, 2004). Different interventions are likely needed in cases of maternal orphanhood, some far more intensive for younger orphans below the age of 5 years and others related to HIV prevention for older pre-teen orphans, many of whom are not fully aware of the potential tragic impact of HIV/AIDS (Watts et al, 2005; Wood, Chase, & Aggleton, 2006).

Few programs attempt to take a developmental approach in designing their orphans and other vulnerable children programs. In designing a comprehensive sustainable orphans and vulnerable children programs program, not only should the age development needs of children be taken into account, but also the diverse family and community development needs. No one organization, partner or donor can provide for all the needs of children in an orphans and other vulnerable children programs program through a family centered approach. The diverse and changing needs of both the children and families require innovative partnerships and referrals. Informal or formal referral networks are necessary to meet the needs of the family as a whole ranging from health care needs, including HIV/AIDS specific, food and nutrition, education, shelter, psychosocial, spiritual, legal support, child protection and household economic strengthening.

The need for social workers or case managers of families who may be secondary caregivers or community volunteers is critical to monitor outcomes in the children and families being supported by an orphans and other vulnerable children programs program (Heymann et al, 2007). Many implementing agencies report working with and utilizing teams of volunteers who are directly recruited by them or by their sub-grantees. They provide the critical gateway into families, counsel parents and children, refer family members to service providers, and monitor outcomes at the child and adult level. Much more needs to be done to provide these volunteers with user-friendly tools that can assist them in their monitoring and evaluation work as well as remuneration for their labor and facilitation of transport in their work and for their patients.

The issue of sustainability comes into the forefront when one considers the glut of interventions that are often child specific without taking into consideration the situation

and needs of the surviving parents and/or other caregivers. Sustainability is a key issue with which many donors, governments and implementing agencies grapple (Starfish interview, 2008; World Vision interview 2008 CCF interview, 2008). This paper offers that sustainability involves building technical and programmatic capacity through training and technical assistance; working with local individuals, organizations, institutions and structures; providing resources (people, currency, commodities, structures) to continue to deliver quality services after external program funds end; and, defining an exit/hand-over strategy with the local community, organizations and individuals. HIV is a chronic illness and therefore must be considered in the long term. HIV services and programs must be designed to continue long after the funding cycle of any one donor.

There are often local individuals, structures, processes and organizations that can be engaged and harnessed so that activities can continue after the orphans and other vulnerable children programs program funded by external funds, individuals and donors ends (Beard, 2005). More effort must be made to build the self-sufficiency of local organizations working with orphans and other vulnerable children to ensure that services and support are neither interrupted nor ceased.

9. Policy and Programming Implications

The policy implications of the results of this review are relevant to policymakers within Ministries of Social Welfare/Social Development/Women and Child Welfare; as well as implementing agencies that include international NGOs, national NGOs, community based and faith based organisations. Governments are the largest and most significant provider of health and social services. They have the overarching mandate to cater for the needs of the poor, the indigent, and the most vulnerable in society.

The need to market the crisis of orphaning as impacting *children only* since children are far more marketable than 'families' needs to be weighed with the need to present the true picture of children with acutely or chronically ill parents/adult caregivers who need support as well. There is an urgent need to portray the plight of struggling *families* who need a 'hand up rather than a hand out' after the crisis period has been brought under control, and the need for more comprehensive support of both adults *and* children in the

family becomes more evident (Richter, Manegold & Pather, 2004). Granted, the need to present children who are the ultimate beneficiaries of a program may bring significant income that can be appropriately disbursed to families and communities in a sustainable manner. However, there are often very few user friendly monitoring and evaluation tools available to track inputs through child sponsorship that end up impacting families specifically and communities, more broadly (CCF interview, 2008).

Through this global literature review, FHI intends to contribute, with the support of the grant from Rockefeller Brother's Fund, to the global evidence base that JLICA is consolidating on best practices in strengthening families, supporting communities, improving access to essential services and promoting appropriate policies. This paper has revealed a considerable gap in documentation of family centered models of care and support for orphans and other vulnerable children programs. Based on the key informant interviews, it is likely that there are a substantial number of orphans and other vulnerable children programs in the sub-Saharan Africa region using components of a family centered model; however, their experiences and lessons learned are not being adequately captured and shared. There is the need to provide guidance to support programs in documenting their experiences. It is also important to look into researching into the costs for implementing family centered programs

It is envisaged that this global literature review will feed into the broader action-oriented research agenda of JLICA and its findings will be incorporated into JLICA's broader advocacy and communications strategy. It is hoped that government, non-governmental and private sector stakeholders will gain insights on the importance of supporting and facilitating the delivery of quality comprehensive services through a child focused, family-centered and community-based approach, in support of children made vulnerable by HIV and AIDS. The project also provides an important opportunity for cross-fertilization and learning between JLICA's LG1 *Strengthening Families*, and LG2 *Strengthening Community*.

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Appendix
Key Informant Questionnaire to Assess Family Centered Approaches in the
Care and Support of Orphans and other Vulnerable Children

Name of Respondent:

Title of Respondent:

Name of Organization:

Date of Interview/Response:

Person Conducting Interview (if applicable):

1. Are you familiar with:
 - a. the UNAIDS/UNICEF 2004 document: *Framework for the Care, Protection and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS?* **Y/N**
 - b. the UNAIDS/UNICEF/USAID 2004 companion document: *Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework of Action?* **Y/N**

2. a) Are you familiar with the five strategies encapsulated in them? **Y/N**
 - b) If Yes, which of the following ones? **Check all that apply.**
 - a. ____ Strategy 1: Strengthen the **capacity of families** to protect and care for orphans and other vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support.
 - b. ____ Strategy 2: Mobilize and support **community-based responses.**
 - c. ____ Strategy 3: Ensure access for orphans and vulnerable children to **essential services**, including education, health care, birth registration and others.
 - d. ____ Strategy 4: Ensure that **governments protect** the most vulnerable children through improved policy and legislation and by channelling resources to families and communities.
 - e. ____ Strategy 5: Raise awareness at all levels through advocacy and social mobilization to create a **supportive environment** for children and families affected by HIV/AIDS.

3. Over what length of time has your organization been involved in HIV/AIDS programs? _____ **years** _____ **months**

4. Over what length of time has your organization been involved in programs that focus on orphans and other vulnerable children? _____ **years** _____ **months**

5. a) Does your OVC program seek to strengthen the capacity of families to protect and care for orphans and other vulnerable children? **Y/N**
- b) If Yes, in which of the following ways? **Check all that apply.**
- a. ____ prolonging the lives of *surviving parents or other adult caregiver(s)* by providing them with/linking them to/facilitating their access to essential health care
 - b. ____ providing HIV/AIDS related health care for the adults *and* children in the family
 - c. ____ providing primary health care for the adults *and* children in the family
 - d. ____ providing *household economic strengthening support* to adults in the family
 - e. ____ providing educational and other essential support to children in order to relieve the *economic strain on the household*
 - f. ____ providing access to vocational training or other skills acquisition in order to improve employment opportunities of *adults and older children* in the household
 - g. ____ providing psychosocial support to the adults *and* children in the family in order to minimize depression and anxiety
 - h. ____ providing spiritual support to the adults *and* children in the family to support their religious belief structures that promote hope
 - i. ____ providing food security and nutrition support to the adults *and* children in the family
 - j. ____ providing shelter support to *the family*
 - k. ____ providing shelter support to vulnerable children or children without adult care in as *family-like structure* as possible
 - l. ____ providing legal support for the protection of the rights of the adults *and* children in the family, including the protection of their assets
 - m. ____ providing child protection support that allows families to *remain intact* without putting any child at risk of harm
6. Does your OVC program partner^{vi} with key service providers i.e. governmental, non-governmental^{vii} and private sector, to provide comprehensive services to adults and children in the families which you serve? **Y/N**
7. Does your OVC program leverage^{viii} the provision of services or resources from governmental, non-governmental and private sector sources, to cater for the comprehensive needs of the entire family? **Y/N**
8. a) Is your OVC program part of an informal or formal referral network (circle which one applies)? **Y/N**
- b) If your program is linked to a formal referral network, are there community volunteers, staff and/or other health and social workers who monitor the capacity of adults and children in families that you serve to cope, grow and thrive? **Y/N**
9. Are the children in your OVC program being regularly monitored at a child and adult outcome level according to specific domain areas^{ix} to assess whether they are thriving under the care of a surviving parent or other adult caregiver? **Y/N**

10. a) Does your program demonstrate sustainability i.e. has it been engaged with a particular community for at least 3 – 5 years; built technical and programmatic capacity through training and technical assistance, worked with local individuals, organizations, institutions and structures provided resources (people, currency, commodities, structures) to continue to deliver quality services after your program ends; and defined an exit/hand-over strategy? **Y/N**

b) If yes, how has your program demonstrated sustainability?

11. Please describe any other aspects of your program that you think are essential to fulfilling the principle in the *Framework* document related to strengthening the capacity of families?

Thank You!

For more information on the Joint Learning Initiative on Children and HIV/AIDS (JLICA), Learning Group 1: Strengthening Families, please visit our web-site at www.jlica.org or contact:

Dr. Linda Richter – Learning Group 1 Co-Chair at lrichter@hsrc.ac.za

Dr. Angela Wakhweya - Learning Group 1 Co-Chair at awakhweya@fhi.org

If you received this questionnaire through a listserv, please email your response to:

Rebecca Dirks at rdirks@fhi.org

ⁱ Defining or supporting any one domain area is essential, but critically important is incorporating intervention (a) and/or (b) to ensure the survival of the parent(s) and/or other adult caregiver.

ⁱⁱ Through a grant, agreement, memorandum of understanding or informal verbal agreement

ⁱⁱⁱ Includes CBOs (community based organizations); FBOs (faith based organizations) and NGOs (non-governmental organizations)

^{iv} Through a formal written or informal verbal request

^v Health, education, food security and nutrition, shelter, psychosocial, child protection, legal protection, household economic strengthening

^{vi} Through a grant, agreement, memorandum of understanding or informal verbal agreement

^{vii} Includes CBOs (community based organizations); FBOs (faith based organizations) and NGOs (non-governmental organizations)

^{viii} Through a formal written or informal verbal request

^{ix} Health, education, food security and nutrition, shelter, psychosocial, child protection, legal protection, household economic strengthening