



LEARNING GROUP 1: STRENGTHENING FAMILIES

CHILD, YOUTH, FAMILY AND
 SOCIAL DEVELOPMENT

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“...families and communities provide the majority of the care and support needed by children affected by HIV/AIDS ”

FAMILY-CENTERED MODELS OF CARE AND SUPPORT FOR ORPHANS AND OTHER VULNERABLE CHILDREN AFFECTED BY HIV AND AIDS

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INTRODUCTION

AIDS continues to be a leading cause of adult mortality worldwide, particularly in Sub-Saharan Africa where over 68% of adults and 90% of children infected with HIV/AIDS live. This has had a profound impact on children and orphaning continues to increase in Sub-Saharan Africa. Countries in Southern Africa, hardest hit by the epidemic, are now experiencing rising proportions of orphans which is shifting care giving to extended kin and grandparents. The impact of HIV/AIDS on children include loss of family and identity, decline in health status and health care, deteriorating nutritional status, increased demands on children for labour and caregiving, and loss of educational opportunities.

Communities and families take up the role of caring for orphaned and vulnerable children. However without government intervention through policy, accessible public services, and income support the task can be daunting. Community based organisations (CBO) and faith-based organizations (FBOs) also play a crucial role. Recently calls have come from families affected by and made vulnerable by HIV/AIDS for the need to strengthen families and support communities in the care for children. A family centred approach is required to assist those who care for children infected and affected by HIV/AIDS.

METHODS

A review of literature related to family-centred models of support to children affected by HIV/AIDS from formal and informal sources was undertaken. The search proceeded from a global literature search of peer reviewed articles to reviews and evaluations of orphan and other vulnerable children programs, including those in the grey literature. Interviews were also conducted to elicit the perspectives of respondents from implementing agencies about family-centred approaches that seek to care for vulnerable children in Sub-Saharan Africa and how the selected agencies integrate such a family-centred approach into the design of their programs that focus on orphans and vulnerable children.

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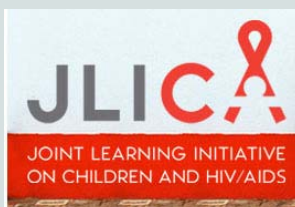
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“Research has demonstrated that children are better able to cope with their vulnerabilities when their adult care giver is healthy and able to provide love and cognitive stimulation.”

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KEY FINDINGS

Overall, we found little literature and few respondents who either defined family-centered care, a strategy for family –centered care or offered a model of a family-centered approach. However, most indicated a familiarity with the strategies defined 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 main strategies defined are; 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.

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 and community.

Despite this, many local non-governmental and community-based organizations working at the grassroots level, who do not always document their experiences in the formal peer reviewed literature 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

Prolonging the lives of parents and providing economic, psychosocial and other support (education, food security, nutrition, health care, shelter, legal support, child protection and spiritual support) can strengthen the capacity of families to protect and care for affected children. However, for families to provide proper care to orphans and vulnerable children, there is a need for wider sectoral responses such as universal access to education and health care. Evidence from several countries indicated that most caregivers require some form of assistance, financial or otherwise, in order to be able to take in the children of kin.

Defining a family-centred approach ...

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.

In the context of this paper, a 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.

KEY FINDINGS

Despite the lack of clearly articulated models, several CBOs provide support to strengthen the ability of families to cope and to continue to care. These approaches are often called community-based rather than family strengthening although they aim to achieve the same goals.

The inclination to portray the crisis of orphaning as impacting *children only* since children are far more marketable than 'families' needs to be weighed against the importance of presenting 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.

•Strategic approaches

Programmes providing support to families at the community level use a number of mechanisms to increase their effectiveness and reach. These include: forming partnerships with other civil society organizations and with government services and programmes; leveraging resources from a range of sources to enable the provision of comprehensive care; and the creation and use of referral networks amongst implementing agencies.

Few programs attempt to take a developmental approach in designing their OVC programs. In designing a comprehensive sustainable OVC 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 OVC program through a family centered approach. The diverse and changing needs of both the children and families require innovative partnerships and referrals.

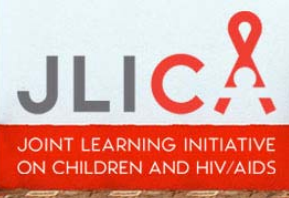
•Capacity building and sustainability

Sustainability of family-centred models need to be examined carefully given the potential cost to programmes that seek 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.

The literature and key informants indicates that programmes have plans for sustainability and building capacity of the community from the outset. But all organisation expressed difficulties in implementing sustainability models in the context of the long-term nature of HIV/AIDS, occurring in the context of poverty, which requires lengthy engagement and investment in communities.

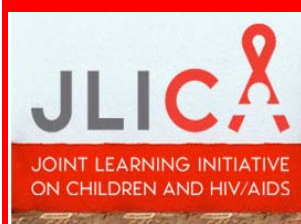
“Interventions need to be tailored to strengthen the intrinsic agency and resilience of the family, especially related to preventing the death of surviving parents, and improving the health of adult caregivers in the extended family “

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“Monitoring child outcomes at the family level including the status of the adults as an indicator of the status of the child is key ...”

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RECOMMENDATIONS

- Agreed working definitions of family-centred and family strengthening approaches are needed. The definition offered in the paper is: 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; psychosocial counseling and support; spiritual support as appropriate; child protection, particularly from abuse and neglect in the care of familiar and affectionate adults; household economic strengthening, and legal support.
- 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 with 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.
- For children whose mothers have died, fathers need to be counseled and supported in taking on the caregiving responsibility and there are some successes to learn from.
- Informal and 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.
- There is a need for materials and tools to be used by community-level workers, as well as methods to assess improvements in child and family wellbeing.
- Family-centre programmes need to be costed, materials developed to support their implementation, and training provided to ensure their quality.