Learning Group 1: Strengthening Families

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“...in countries hard-hit by the HIV epidemics in southern Africa, AIDS is best thought of as a family disease”.

Introduction

The Joint Learning Initiative on Children and AIDS (JLICA) adopted the key strategies of the 2004 Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS for the work of the Learning Groups. Learning Group 1 focused on Strengthening Families, the first key strategy in the Framework, stated as “Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support”.

Apart from the fact that families form the most fundamental and lifelong support system for children, there are three principle reasons for specifically focusing on families in efforts to support children affected by HIV and AIDS. Firstly, in countries hard-hit by the HIV epidemics in southern Africa, AIDS is best thought of as a family disease. This accurately reflects the sexual and vertical transmission of HIV and acknowledges that HIV clusters in families. Secondly, it is families who carry the heaviest load in treating, caring for and protecting children and other members directly affected by the epidemic. Thirdly, well-functioning families play a fundamental, but as yet not fully recognised role, in the prevention of HIV transmission.

AIDS in high HIV prevalence countries needs to be approached as a family disease because transmission occurs mainly through family relationships. In the worst affected regions, the majority of new infections, estimated between 60% and 95% in Rwanda and Zambia, occur between stable cohabiting partners who are likely to be parents, as well as between parents and children through vertical transmission. This means that households, as well as extended family and kin networks are likely to experience repeat morbidity and mortality that saps what resources they have.

Methods

LG1 established an Advisory Group to help frame the key questions to be addressed in its work. Twelve detailed papers were commissioned, each comprising a systematic review and analysis with recommendations for policy. The Group met, face-to-face twice, and in sub-group meetings made possible by conference opportunities and the like, through telephone conferences and calls and emails. Each paper was reviewed by three people representing the fields of research, practice and policy. A selection of the papers is in publication in a special issue of AIDS Care. Several authors have and are in the process of publishing aspects of their work in other journals and reports.

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“The most effective, scalable and sustainable strategy for children is to strengthen the capacity of families to provide better care for more children”.

A comprehensive review of the impacts of HIV and AIDS on children and families, as was undertaken in the JLICA’s Learning Group 1 on Strengthening Families, directs efforts to three avenues for providing support to families. These are economic strengthening through income transfers to the poorest households, adopting a family-orientation to the provision of HIV and AIDS services, and providing specific services to enhance children’s development.
LEARNING GROUP 1: STRENGTHENING FAMILIES

FINDINGS

1. In high-prevalence countries, HIV/AIDS is a family matter. Transmission occurs predominantly between cohabiting partners and from parent to child. Family-focused treatment, care and support services, as well as prevention efforts, support families as well as help to expand access to those people most at risk of, and affected by, HIV and AIDS.

2. Families, peers, 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. Less than 1 percent of orphans in sub-Saharan Africa are estimated to be living outside of family care. Only a very small proportion of AIDS-affected children and families, estimated to be under 15 percent, are currently reached by any efforts additional to support they receive from kith and kin. The most effective, scalable and sustainable strategy for children is to strengthen the capacity of families to provide better care for more children.

3. HIV and AIDS affect many children, not only those children whose parents have died. Children become infected with HIV, and are affected by the illness of parents and caregivers, the migration of adults and children into and out of their households, the loss of income and livelihood support provided by breadwinners, stigmatization in the community, and deterioration of health and education facilities due to HIV infection among service-providers. High HIV prevalence in sub-Saharan Africa occurs in the context of extensive and deep poverty. Many children live in destitution. Under these conditions, targeting programmes and services exclusively to orphaned children is neither appropriate nor effective. Inappropriate targeting contributes to stigma and discrimination against children and families affected by HIV and AIDS.

4. The vast majority of affected children, including orphaned children (over 95%), live in families. Despite the difficulties involved, extended kin continue to foster and care for children of relatives. This must be maintained, because families are the

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“Poor families have fewer resources and reduced capacity to deal with morbidity and mortality, mainly because they have less income and food security and few, if any, assets and savings.”
“... policy makers, funders, and programme implementers must make better use of evidence, the results of good research must be widely disseminated, and approaches that are contra-indicated by good research must be challenged.”

FINDINGS & RECOMMENDATIONS

best environment for children, families generally have children’s best interest at heart, and they comprise a stable and consistent environment for children. However, only 15 percent of affected families are reached by support agencies beyond kin and kin. This is affecting the capacity of families to protect children from the worst effects of poverty, deprivation and loss. Given the programme experience already available, income transfer programmes should be implemented without further delay, by bringing together the combined skills of government, civil society organizations and donors.

5. Families must be strengthened, most specifically through efforts to achieve universal access to health and education, family-focused services, as indicated above, and through social protection, including income transfers. The evidence that income transfers will relieve distress, and increase consumption, especially for children, is very good. Given the programme experience already available, income transfer programmes should be implemented without further delay, by bringing together the combined skills of government, civil society organizations and donors.

6. An extensive review demonstrates that the problems experienced by children and families in low-prevalence and concentrated epidemics are very much like those experienced by children and families in high-prevalence environments. Impoverishment and isolation, due to stigma and discrimination, cause children’s care, nutrition, and schooling to deteriorate, and prompt increased demands on their labour. Many of the conclusions reached and recommendations made in this report are thus also applicable to low prevalence settings.

CONCLUSIONS

To date, children and families have been very severely neglected in the HIV/AIDS response. Support for affected children has been left largely to families, extended kin and communities.

As a result of initiatives such as the JLICA, and the vigorous advocacy of a number of child-oriented agencies, the spotlight is slowly moving to children. The current response is composed of small, localised, largely serendipitously-located projects reaching at most a few thousand children with services of uncertain effectiveness. But projects of this kind can only take us so far. To have bigger impact requires larger and more systemic responses.

It is clear that impacts on children are mediated by families, as are the prospects for providing sustainable assistance for children over the long-term. The capacities of families to protect children and to compensate for their loss of caregivers, security, possessions and the like, is highly dependent on the social context, most especially, pervasive and enduring poverty and labour migration. For this reason, access to essential services, such as health and education, as well as basic income security, must be at the heart of national strategic approaches.

Income transfers, in a variety of forms, are desperately needed and positively indicated by available research. Basic economic security will relieve the worst distress experienced by families, enable them to continue to invest in the health care and education of their children, and to pay for their share of the costs involved in receiving treatment and care, such as transport to health facilities and additional food. Money is needed in and of itself, but it can also facilitate access to other services and amplify their benefits.