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Strengthening families to support children affected by HIV and AIDS

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This paper provides an overview of the arguments for the central role of families, defined very broadly, and we emphasise the importance of efforts to strengthen families to support children affected by HIV and AIDS. We draw on work conducted in the Joint Learning Initiative on Children and AIDS's Learning Group 1: Strengthening Families, as well as published data and empirical literature to provide the rationale for family strengthening. We close with the following recommendations for strengthening families to ameliorate the effects of HIV and AIDS on children. Firstly, a developmental approach to poverty is an essential feature of responses to protect children affected by HIV and AIDS, necessary to safeguard their human capital. 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. Secondly, we need to ensure that support garnered for children is directed to families. Unless we adopt a family oriented approach, we will not be in a position to interrupt the cycle of infection, provide treatment to all who need it and enable affected individuals to be cared for by those who love and feel responsible for them. Thirdly, 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 and enable them to continue to invest in the health care and education of their children. Lastly, interventions are needed to support distressed families and prevent knock-on negative outcomes through programmes such as home visiting, and protection and enhancement of children's potential through early child development efforts.

Keywords: families; children; HIV/AIDS; social protection; cash transfers; family services

Introduction

From the moment children affected by HIV and AIDS came into the spotlight, they have been portrayed as abandoned and alone. There are pictures of emaciated infants dying on their own because they have no access to treatment, and images of orphaned children, unaided and unaccompanied (Bray, 2003; Meintjes & Giese, 2006).

Our shared humanity and global duty to protect the rights of the most vulnerable people make the suffering of children in the wake of the AIDS epidemic the responsibility of all. However, with respect to children affected by HIV and AIDS, we seem to have gone too far – we see only the figure, the child, but no ground; we seldom see their caregivers and families, despite their great need for assistance. Yet, it is a mother, father, aunt, grandmother or older

brother who brings a sick child to the clinic, and the same people who feed, clothe and care for orphans and children affected by HIV/AIDS in other ways – in most cases, as best as they can (Richter, Foster, & Sherr, 2006). Indeed, some approaches have pitted parent against child and some have called for sacrifices and choices rather than harmony and integration.

Children everywhere are, can and should be, connected to adults and other children, through family, kin and clan networks. The need for this is heightened at times of stress, illness or challenge. Family care is our species-specific cultural adaptation to ensure children's growth, learning and socialisation. As human beings, our neurophysiological functioning, emotional regulation and cooperative learning, are tailored to function optimally in stable,

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secure and affectionate relationships with others. For children, especially young children, this is critical (Richter, 2004). In the absence of these social conditions, regardless of the material environment, children grow poorly, fail to thrive, show delayed language, cognitive and motor development and display inappropriate emotional and interpersonal behaviour. This pattern of poor development is seen most clearly in children placed in orphanages at a young age (Frank, Klass, Earls, & Eisenberg, 1996; Lis, 2000). The effects of distorted early development can be long lasting and manifest themselves in due course in disturbed parenting, thus resulting in a transgenerational negative effect.

For this reason, family reunification and family placement are critical in response to children displaced from family and kin during national disasters, war and the displacement of communities (Ressler, Boothby, & Steinbock, 1988). However, we have not seen the same emphasis on family reunification, placement and support in efforts to support children affected by HIV and AIDS, especially as a result of adult mortality. Instead, there has been a proliferation of orphanages, many funded through the faith sector. Furthermore, discourse about so-called *AIDS orphans* emphasises direct service provision to children, including psychosocial support and interventions, but seldom stresses the importance of promoting and supporting family care. The very definition of an orphan is overinclusive, thereby labelling bereaved children with a surviving parent as “orphans” despite the vital importance of support for surviving parents (Sherr et al., 2008).

The Joint Learning Initiative on Children and AIDS (JLICA) calls for a complete turnaround in this approach, accentuating the need to reinforce families’ long-term caring capacities as the basis of a sustainable response to children affected by HIV and AIDS, and the need for family centred services integrating health, education and social support (see Editorial by Richter & Sherr).

In this paper, we set out the arguments for the central role of families, by which we mean the wide range of structures that comprise networks of mutual commitment including families of origin and families of choice (Lovejoy, 1989); and we emphasise the importance of efforts to strengthen families to support children affected by HIV and AIDS. We draw on work conducted in the JLICA’s Learning Group 1: Strengthening Families, as well as published data and empirical literature to provide the rationale for family strengthening. We close with a set of recommendations for strengthening families to ameliorate the effects of HIV and AIDS on children.

Families and HIV/AIDS

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 that carry the heaviest load in treating, caring for and protecting children and other members directly affected by the epidemic; and, 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 (Dunkle, Stephenson, & Karita, 2008), as well as between parent and children through vertical transmission (De Cock et al., 2000). This means that households, as well as extended family and kin networks that are linked together across households, are likely to experience repeat morbidity and mortality that saps what resources they have or are able to continue garnering.

A district-level analysis in southern Africa indicated that, while 32% of families had been directly affected by HIV and AIDS, another 29% (totalling more than two-thirds) had experienced ripple effects from obligations to foster affected children and assist relatives with money for food and health care expenses (Cornia, 2007). The numbers of affected households (those estimated to have an adult member living with HIV, an adult member with AIDS, and those who have experienced one or more deaths of adult members from AIDS) were estimated in 2003 to range from about 16 to 57% in 11 Sub-Saharan African countries (Belsey, 2005).

Families have also led in responses to provide comfort and care to those who become sick and vulnerable as a result of HIV and AIDS. All over the world, the family is the *de facto* haven for family members who are ill or in trouble (Pequegnat & Bray, 1997). But families are *absolutely* the last resort when there are few, if any, formal safety nets or state provision – as is the case in most resource-poor countries. The poorest families, who cannot pay for services and other facilities to lessen their burdens, have absorbed the greatest force of impact. They have

done this by diversifying their livelihoods – including through migration – to compensate for lost income and labour; they have financed the health care of those who are sick; provided home palliative care, assisted and absorbed kith and kin. This has been done, by and large, by reducing consumption – eating less and spending less on education and health care, all of which affects the immediate and longer term wellbeing of children (Donahue, 2005; Heyman, Earle, Rajaraman, Miller, & Bogen, 2007; Phiri & Tolfree, 2005). Family breakdown is correlated with negative individual health and wellbeing outcomes, while family strengths are important source of resilience.

Lastly, families play a key role in HIV prevention. Labour migration entailing the separation of spouses, has facilitated the spread of the virus (Brummer, 2002), and studies show that the quality of parent–child relationships is strongly associated with HIV risk in adolescence (Gregson et al., 2005). Parental monitoring and supervision is related to delayed sexual debut, and adolescents who report being emotionally distant from their families or feel unsupported are more likely to engage in sexual behaviours at a younger age (Youngblade et al., 2007). Lastly, several studies show that orphaned children may be at heightened risk for HIV infection, with the findings being stronger for young women than men. Orphans have been found to have younger sexual debuts and more sexual partners (Operario, Pettifor, Cluver, MacPhail, & Rees, 2007; Thurman, Brown, Richter, Maharaj, & Magnani, 2006) and two studies in Zimbabwe (Birdthistle et al., 2008; Gregson et al., 2005) have found female orphans more likely to be HIV-positive, have sexually transmitted infections or have been pregnant than non-orphaned peers. Because families are the most proximal and fundamental social system influencing human development, they provide critical entry points for effective and lasting behaviour change as well as protection (Pequegnat & Szapocnik, 2000).

Children and families

The family is the point of interaction between adult infection, adult illness and child wellbeing. It is within the family that care for children is provided in a natural and sustainable way and where care is compromised when the family is under strain.

To date, however, the focus of the international community, funders and implementers, has been almost exclusively on children orphaned by AIDS, with many programmes attempting to provide services and support directly to children (Desmond, 2008a, 2008b; Wakhyewa, Dirks, & Yeboah, 2008).

Parental deaths – that is, the death of a mother, father or both – used as an indicator of maturity of the epidemic (Whiteside & Barnett, 2006), have increased markedly, especially in Sub-Saharan Africa. In 2007, 12.1 million children in the region were estimated to have lost one or both parents to AIDS (UNAIDS, UNICEF, & WHO, 2008). This comprises approximately 37% of all orphaning.

Given the increase in adult mortality and the age profile of those people who are dying, it is critical that we be concerned about orphans – but we should not be limited in our response, nor lose our sense of families as the most important networks for affected children. As far back as 1990 it was noted that, what was then called *the orphan problem*, was “just the tip of the iceberg” of social and economic disruption (Hunter, 1990; Prebble, 1990). Moreover, several studies indicate that, as a result of widespread poverty and deprivation in the worst affected regions, orphans are seldom worse off than other very poor children (United Nations General Secretary Report, 2006).

As indicated, of the majority of children classified as an orphan, the vast majority have a surviving parent. In addition, the vast majority of orphaned children, an estimated 95%, live with surviving members of their family (Hosegood, 2008; Richter, 2008). These facts lead to a fundamental conceptual, policy and programme shift from efforts to assist children affected by AIDS towards family support, so that families can assume their rightful role of caring for and protecting children – with the support of the state and non-governmental organisations.

Many surviving parents are themselves vulnerable; they may be infected, ill and/or in economically helpless circumstances. However, it is important to understand what families most need to enable them to continue to protect and nurture children in their care. Maternal death from HIV is a strong predictor of future paternal death, which points clearly to the need to prioritise treatment to surviving parents to avoid orphanhood.

Vulnerable families

While families are vulnerable, there are few signs that families *per se* are disintegrating (Madavan & DeRose, 2008; Mathambo & Gibbs, 2008). In fact, Hosegood’s (2008) review concludes that while adult deaths can lead to decline in household size, AIDS-affected households are generally able to replenish their adult membership numbers. Given the poor socioeconomic state of the region, there is no shortage of adult labour available for the care of children.

A great deal of attention is being focused on child headed and skip-generation households as manifestations of family weakening in the face of HIV and AIDS. Service programmes report precipitous increases in both of these extreme household forms (Arnab & Serumaga-Zake, 2006). However, this trend is not supported by population-based data derived from national household surveys and Demographic Surveillance Sites. Rates of child-headed households from these sources are seldom above 1–2% (Floyd, Marston, Hosegood, Scholten, & Zaba, 2005; Hill, Hosegood, & Newell, 2008; Hosegood et al., 2007; Madhavan & Schatz, 2007; Monasch & Boerma, 2004; Richter & Desmond, 2008), and many reported instances are found to be data errors. The results from these, and other studies, suggest that such extremely vulnerable households may emerge following the death of an adult, but they tend to be temporary with adults moving in to care for children, or children moving to join other households. Similar findings have been reported with respect to skip-generation households. They are not common; the majority of older people (87%) tend to live, not only with children, but also in three-generational households (Hosegood & Timæus, 2005).

Orphanages, funded largely by the faith sector (Singletary, 2007), are increasing as a result of misperceptions that orphaned children are alone and have no family, that families are disintegrating, and that there are no adults to care for children other than aged grandparents (Cross, 2001). When asked, affected communities, families and children prefer family and community care over orphanage care, and families are generally willing to care for the affected children of kin (Freeman & Nkomo, 2006; Phiri & Tolfree, 2005). However, the capacity of families to take in children is severely limited by their already brutally constrained economic conditions. For this reason, income support is a critical aspect of family strengthening. Institutional care not only has established adverse effects on children's development and social relationships (Frank et al., 1996), but is also extremely expensive, costing up to 10 times what families in the same communities need to provide for a child (Desmond, Gow, Loening-Voysey, Wilson, & Stirling, 2002). Orphanages, which most frequently care for poor, rather than orphaned children, thus divert much needed support away from families.

The need to support families is also important because the response by families has come with costs, sometimes also to their integrity and functionality. Household dissolution, abandonment, neglect of informally fostered children of relatives, property grabbing and abuse has all been recorded (Abebe &

Aase, 2007; Richter, Manegold, & Pather, 2004). These anomalies do not detract from the importance and the need to support families. Rather, they emphasise the need for social protection, including stronger mechanisms of social justice and social welfare in highly affected communities. Given the primary role families are playing in responding to the epidemic, strengthening the capacity of families through systematic, public sector initiatives has been identified globally as one of the most important strategies (Foster, Levine, & Williamson, 2005).

Strengthening families

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. Each of these approaches is discussed in more detail below.

Economic strengthening

HIV and AIDS generate and intensify poverty at the household, community – and, over time, the country level (Collins & Leibbrandt, 2007). 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. They thus have no cushion by which to absorb reductions in income, livelihood and labour, coupled with increased human and financial costs of home care, medical and other treatment, burial and potential relocation (Cornia, 2007; UNAIDS, 2000).

Impacts also seep upwards through their effects on children's development, mental health (Earls, Ravioli, & Carlson, 2008), family capacity and recycled vulnerability to HIV infection and poverty (Bell, Devarajen, & Gerbash, 2006; Belsey, 2005). AIDS has more than wiped out child survival gains achieved during the 1980s. A study of 40 countries shows that a 1% increase in adult HIV prevalence raises the under-five mortality rate by 1.9 per thousand (Cornia, 2007). High HIV prevalence is associated with the highest under-five mortality rates and increases in mortality between 1990 and 2006 (Bryce et al., 2008). Nutrition of children is affected by reduced family consumption. Caregivers juggle many competing family needs in the face of scarce resources (Drimie & Casale, 2008).

While this paper has referred mostly to southern and Sub-Saharan Africa, a review of 363 papers on children in low prevalence and concentrated epidemic communities draws the same conclusion (Quality Assurance Project, USAID Health Care Improvement Project, & UNICEF, 2008). The review found that HIV-affected households everywhere experience a worsening of their socioeconomic status, specifically as a result of income losses due to declining productivity, and expenditure increases related to health. They are also more likely to become indebted, to sell off assets and to reduce consumption, especially food. While many children affected by HIV/AIDS in low prevalence countries already were living in poor households, HIV infection in the household worsens the overall household economic status.

Increasing poverty, and its knock-on effects on children, as well as the family as a social institution which exists to transfer inter-generational benefits – not disadvantages – suggest a social wage and social security approach to assist the neediest families as an urgent first step. Access to water, sanitation, education and health services are also provisions that would significantly assist the poorest communities affected by HIV and AIDS (Desmond, 2008a, 2008b).

There is a continuum of social protection strategies, ranging from micro-lending such as Bangladesh Rural Advancement Committee (BRAC) in Bangladesh, work initiatives such as Botswana's Labour-Based Relief Programme and skill training programmes. However, the degree of incapacity of the worst hit and poorest families affected by HIV and AIDS means they cannot benefit from up-stream developmental approaches. Income transfers are less labour intensive and require less administration than in-kind benefits, and they maximise the choices of poor families. They can be implemented immediately in collaboration with local civic organisations, and scaled up as capacity and funds allow. Whether conditional on accessing services of benefit to children and families or not, they provide a right-based approach to providing immediate relief. At the same time, they promote human and social capital thus building capacity to fight HIV/AIDS and recover from its impacts (Adato, 2007; World Bank, 2008).

Income transfer programmes can take many forms, including old-age pensions and child grants. But it is essential to immediately initiate income assistance to the most needed households. In high prevalence countries in Africa, income assistance is a critical entry point and basic platform for HIV/AIDS prevention, treatment and care. The amounts involved in providing small income transfers are low relative to total foreign aid. If a recent Zambian pilot providing \$15 per month to each of the poorest 10% of households, was implemented in all low income countries in

Sub-Saharan Africa, then it would cost only 3% of the aid to Africa agreed at Gleneagles (DFID, 2005).

Family oriented HIV and AIDS services

All HIV and AIDS prevention, treatment and care services lend themselves to a family focus in generalised epidemics; for example, HIV testing among couples and even whole households is proving promising (Bateganya, Abdulwadud, & Kiene, 2007; Chomba et al., 2008; Zhou, 2007) and is cost effective (Postma et al., 2002). Prevention of mother-to-child transmission therapy (PMTCT), especially, suggests itself as an entry point to family networks to provide multiple services.

Family focused studies of adult anti-retroviral therapy (ART) indicate very significant benefits for children in the household. A longitudinal micro-economic study in Kenya demonstrated that adults on treatment were able to resume working, and that their return to work was associated with two important child benefits – reduction in child labour and children's resumption of schooling. A second study confirmed the impact of adult ART on child schooling, and also showed a benefit to children's nutrition and growth (Kimou, Kouakoa, & Assi, 2008; Thirumurthy, Zivin, & Goldstein, 2006).

Families can also contribute meaningfully to treatment success. A recent study in South Africa reporting very high ART adherence rate among children on treatment cared for by HIV-positive caregivers, suggests that an important paradigm shift is needed – “in the way we think about families infected with HIV: instead of families ‘ravaged’ or ‘devastated’, perhaps we might consider that if given access to treatment through a family-centred model, those on treatment can instead be a source of unity, continuity, knowledge, and strength for pediatric patients and other HIV-infected family members” (Reddi & Leeper, 2008, p. 907). Fatherhood and fathering is poorly tracked and appreciated, despite the fact that fathers play a key role in child development, decision making and are a resource for the family (Sherr & Barry, 2006). Sibling bonds are protective, provide strong relationships and a source of continuity in the face of family challenge (Gass, Jenkins, & Dunn, 2007), yet avoidance of sibling separation has yet to be prioritised in HIV policy.

Services to enhance children's development

The focus on orphaned children has framed mitigation for children affected by HIV and AIDS as an individual, rather than a national or social problem. Against a background of deepening poverty, the numbers of children made vulnerable by the epidemic

are increasing. In most parts of southern Africa, an estimated 65% of children live in poverty, and about 80% are severely deprived of basic amenities, nutrition and safety (Gordon, Nandy, Pantazis, Pemberton, & Townsend, 2003). In such situations, consideration of impacts of HIV and AIDS concern most children.

Under these conditions, support to individual children, while needed at a local level, is insufficient to reach all needy children and unable to reduce the numbers of children made vulnerable by poverty and HIV and AIDS (Richter et al., 2006). In contrast, a “public health”, or systemic approach is one in which attempts are made to reduce the total number of children needing assistance. This can be done by, amongst others, social protection, state-supported preschool programmes, free education and health care, school feeding and removing barriers to access (Richter & Desmond, 2008).

In a comprehensive review for Learning Group 1, Chandan & Richter (2008), examined well-evaluated programmes to improve the family care environment. These included home visiting, parent education and parent behavioural skills training, two-generational (child development and parental wellbeing) and combined early child development and youth development programmes.

Parenting and family support programmes generally include a package of services and support, which vary depending on the needs of the particular families, but they usually contain one or more of the following components: parenting education, parent skill building, home visiting, social support, counselling services, case management services, health care provision, early childhood education, adult education and job training, financial assistance and advocacy (Comer & Fraser, 1998; Layzer, Goodson, Bernstein, & Price, 2001).

Home visiting programmes, in particular, seek to improve outcomes for children by targeting parenting knowledge, beliefs and practices and by providing social support and practical assistance. In the main, they are prevention programmes, seeking to avert future problems by working with parents when children are young (Gomby, Culross, & Behrman, 1999; Olds, Hill, Robinson, Song, & Little, 2000).

Early childhood development programmes are generally targeted towards children and families living in poverty, and are intended to counteract the factors that place low income children at risk of poor outcomes. Two-generation programmes and “combination programmes” (Karoly et al., 2005) offer early childhood programmes in combination with parenting education as well as adult education, literacy or job skills and training.

In examining the evidence on family strengthening from high income contexts and considering its

applicability to high prevalence, resource constrained settings, two key areas, home health visiting for pregnant mothers and young children as well as early childhood development programmes emerge as areas of appropriate and promising intervention. Home health visiting programmes could build upon existing structures of home-based care (HBC) programmes in Sub-Saharan Africa which have become an established intervention strategy for meeting the healthcare needs of people living with HIV and AIDS (Campbell, 2004; World Health Organization, 2000).

However, some important caveats are in order. While it is useful to learn from successful and effective programmes, many challenges attend the implementation of interventions tested and refined in resource-rich countries, given the huge gap in what is feasible in poorly resourced contexts. Well-trained professional staff, high quality programmes and programme delivery, high density or dose of programme elements and integration with other services have all been identified as essential for programme successes (Brookes, Summers, Thornburg, Ispa, & Lane, 2006). It is also important to have in place social welfare services to respond to and prevent any family based negative input.

It is clear that implementation of family strengthening programmatic activities must either unfold alongside or build upon efforts to economically strengthen families. They are, in fact, complementary pieces of the same puzzle.

Conclusion

To date, children and families have been very severely neglected in the HIV/AIDS response. There was a delayed response to children with respect to prevention and treatment, to start with, and access for children continues to lag significantly in technology, support, access and roll out in comparison to adult services. 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. By and large, these services provide psychosocial support in the form of home visiting and companionship, and poverty alleviation through distribution of food, uniforms and payment of school fees. These efforts undoubtedly alleviate some of the distress experienced by children and families. But projects of this kind can only take us so far. To have bigger impact, it requires larger and

more systemic responses on which local initiatives can build.

It is clear that impacts on children are mediated by families, as are the prospects for providing sustainable assistance for children over 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. This makes a developmental approach to poverty, an essential feature of responses to protect children affected by HIV and AIDS and to safeguard their human capital. 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.

We need to ensure that support garnered for children is directed to families. In the highest-prevalence countries, HIV and AIDS cluster in families. It is through worsening household conditions that children are adversely affected, and in families where they will find the emotional and material resources to withstand and recover from the effects of the epidemic. Given the long-time scale of HIV and AIDS, children now will be parents in their own families within one or two decades. Unless we adopt a family oriented approach, we will not be in a position to interrupt the cycle of infection, provide treatment to all who need it, and enable affected individuals to be cared for by those who love and feel responsible for them. Attempting to prevent, treat and care for one individual at a time, as if they are unlinked to others in their social and familial networks, is neither strategic nor efficient in high prevalence situations where up to a third of all households are directly affected by the epidemic.

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. Income transfers are not the *solution* to children and HIV/AIDS. Rather, income transfers are the entry point to large scale integrated national responses to children and families affected by HIV and AIDS. Money is needed in and of itself, but it can also facilitate access to other services and amplify their benefits. In addition, interventions are needed to support distressed families and prevent knock-on negative outcomes through programmes such as home visiting, and protection and enhancement of

children's potential through early child development efforts.

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