### Strengthening families through early intervention in high HIV prevalence countries

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Families have been at the forefront of the response to the HIV/AIDS epidemic in high-prevalence countries. They have also borne the greatest costs associated with the epidemic, including impoverishment, which has strained their capacity to care for vulnerable members. Within this context, there is consensus that strengthening the capacity of families to care for children is one of the most important strategies for mitigating the impacts of the HIV/AIDS epidemic on children's lives in high-prevalence countries. It is argued that evidence-based early intervention programmes that enhance caregiving and link caregivers with supports and services can play a pivotal role in strengthening families. Based on a systematic review, we recommend that two intervention strategies that should be given consideration within the context of high-prevalence countries, because of their demonstrated benefits in other settings, are nurse home visiting for first time, low-income pregnant mothers and their young children as well as early childhood development programmes for low-income children and families.

Keywords: strengthening families; high prevalence; early intervention; poverty

### Introduction

Families are the single most important locus of care and protection for children (American Academy of Pediatrics, 2003), and children are inextricably dependent on the resources, capacities and well-being of families.<sup>1</sup> This is especially the case in the context of high HIV prevalence where families have been the frontline response to the epidemic (Heyman, Earle, Rajaraman, Miller, & Bogen, 2007; Phiri & Tolfree, 2005), and have also absorbed the greatest social and economic costs associated with its everyday impacts (Donahue, 2005).

Within this context, it has become clear that strengthening the capacity of families through large scale, public sector initiatives is one of the most important strategies for "building an effective response" for mitigating the impacts of the epidemic on children (Foster, Levine, & Williamson, 2005). The Framework for the Protection, Care and Support for Orphans and Vulnerable Children Living in a World with HIV and AIDS identifies "strengthen(ing) 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" as one of five key strategies (UNAIDS/UNICEF, 2004). Its companion document, Enhanced Protection for Children Affected by AIDS, makes the important point that investing in family support services is a critical aspect of social protection (UNICEF, 2007).

While there is agreement on the need to strengthen families, consensus on *how* best to strengthen families is still emerging. This article contributes to the consensus-building process on how to strengthen families and improve the lives of vulnerable children within the context of the HIV epidemic in highprevalence countries. It summarises the main conclusions of a detailed review commissioned by the Joint Learning Initiative on Children and HIV/AIDS (JLICA) which synthesised the evidence on carefully evaluated family strengthening interventions<sup>2</sup> in high income countries in fields other than HIV and AIDS and assessed their applicability to high-prevalence resource-constrained countries (see Chandan & Richter, 2008).

While the JLICA review paper discusses the evidence for a range of family strengthening programmes for families and children across the age spectrum (0–18 years), this article focuses specifically on the evidence for early childhood interventions.<sup>3</sup> We conclude that high-quality home visiting for first-time, low-income pregnant mothers and their young children as well as early childhood development (ECD) programmes for low-income children and families hold considerable promise as strategies to strengthen families in the context of high HIV prevalence, resource-constrained settings and should be given careful consideration on a country-by-country basis.

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# HIV/AIDS and the risks to children's development in high-prevalence countries

It is difficult to overestimate the risks to children's development in high-prevalence countries, the preponderance of which are in Sub-Saharan Africa (SSA). Two-thirds of all people living with HIV (25 million people) reside in the region, and AIDS is the leading cause of death among adults aged 15–59 in SSA (UNAIDS, 2006). By 2010, it is estimated that 15.7 million children in SSA will have lost one at least one parent to AIDS. In addition, many more children are living in communities severely affected by the epidemic, where HIV has eroded the capacity of schools, health facilities and social services to meet the everyday needs and rights of children (UNAIDS/ UNICEF, 2004).

Although not all children affected by the epidemic are vulnerable, without appropriate interventions many children affected by HIV/AIDS,<sup>4</sup> will face serious risks to their health and development. Often, the direct impacts on children's lives begin with infection in the family and engender related difficulties, such as the disruption or loss of parental care, increased poverty, food insecurity and malnutrition, withdrawal from school, decreased access to healthcare, increased participation in work and livelihood activities, psychosocial distress, stigma, as well as increased risk of abuse and HIV infection (Hunter & Williamson, 2000; Richter, Manegold, & Pather, 2004).

With some exceptions, high-prevalence countries in SSA are also some of the poorest in the world; as such, the epidemic has both unfolded within a context of pervasive poverty and also intensified poverty (Bachmann & Booysen, 2006; Barnett & Whiteside, 2002). Many children and families affected by HIV/AIDS are destitute or living under considerable economic duress.

Under such conditions, there is general consensus that enhancing protection for children affected by HIV/AIDS necessitates large scale interventions that strengthen international, national and community level responses for all vulnerable children (UNICEF, 2007). Indeed, an exclusive emphasis on HIV/ AIDS-related child vulnerability can infringe the rights of other vulnerable children as well as stigmatise children and families affected by HIV/AIDS. Moreover, assuming an inclusive approach to child vulnerability through economic targeting or efforts to realise universal access to education and health care, for example, are particularly relevant for high-prevalence countries where the need for systems strengthening in the public sector (education, health and social welfare) is part of a broader developmental agenda and human rights imperative.

### Why early intervention and why focus on caregiving?

A time of rapid neurological development, it is undisputed that early childhood is the most critical, sensitive period in a child's life. More than any other time, children require responsive caregiving, stimulating learning opportunities, sufficient nutrition and timely healthcare (Shonkoff & Phillips, 2000).

However, in resource-constrained countries, many young children under the age of five are exposed to multiple risks which compromise their "developmental potential" and have detrimental effects on their cognitive, motor and social–emotional development. These risk factors include poverty, malnutrition, lack of stimulation, maternal depression and exposure to violence (Grantham-McGregor et al., 2007). In many high-prevalence countries, where poverty and chronic food insecurity are enduring challenges, HIV is yet another risk factor which can negatively impact young children's development.

Children of all ages are vulnerable to the adverse impacts of the HIV/AIDS epidemic, and children in middle childhood and adolescence are more likely to lose a parent to AIDS because of disease maturation. However, impoverished young children are especially vulnerable because of their developmental stage. Not only is the young child's brain developing and malleable, young children's developing systems makes them particularly susceptible to malnutrition and disease which can have knock-on effects on their long-term health and well-being (Dunn, 2005). Recent research indicates that material deprivation and poor health in childhood, including under-nutrition, can have lasting impacts on educational achievement, adult health and economic productivity (Case, Fertig, & Paxson, 2003; Victora et al., 2008).

Conversely, investments in evidence-based early intervention programmes yield important and longlasting benefits for children, families and society at large (Karoly, Killburn, & Cannon, 2005). Indeed, it has been demonstrated that the economic returns on interventions in early childhood are higher than at any other time in life (Heckman, 2006). Well-designed early childhood interventions implemented in the West have been found to generate a return to society ranging from \$1.80 to \$17.07 for each programme dollar spent (Karoly et al., 2005).

While mitigating the material effects of poverty is critical for improving outcomes for young children at risk, findings from neuroscience also demonstrate the importance of sensitive, responsive care for the healthy development of young children under the full range of socioeconomic circumstances (Shonkoff & Phillips, 2000). While caregiving under any conditions can be challenging, within the context of

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poverty and HIV, it is likely to be especially stressful. Indeed, there are indications that HIV in the family, and maternal HIV in particular, can compromise the healthy development of children. Both infected and uninfected children of HIV-positive mothers, for example, are at increased risk of various developmental disturbances and delays (Brandt, 2005; Sherr, 2005) as well as decreased mortality (Hong, 2008). While the mechanisms at play are not clearly understood, it has been argued that one of the main *indirect* effects of maternal HIV on infants is compromised parenting, mediated by poor maternal mental health (Stein et al., 2005).

Within this context, evidence-based programmes that seek to enhance caregiving and provide caregivers with supports and services can play an important role in mitigating the compounded negative impacts of HIV/AIDS and impoverishment on the development of young children.

# The evidence for nurse home visiting for low-income first-time pregnant mothers

Home visiting is a commonly used strategy to support vulnerable families with young children in the USA and the UK. These programmes seek to improve outcomes for children by targeting parenting knowledge, beliefs and practices and by providing families with social support and practical assistance (Barlow, 2006; Gomby, Culross, & Behrman, 1999; Hanson, Morrow, & Bandstra, 2006). Although the evidence for the effectiveness of home visiting, as a whole, is mixed (Gomby, 2005; Raikes et al., 2006; Sweet & Applebaum, 2004), some programme models have demonstrated effectiveness. The most conclusive evidence comes from the Nurse Family Partnership (NFP) in the USA, a community health programme that aims to improve pregnancy outcomes, child health and development, and maternal life course. The programme targets first-time, lowincome mothers from pregnancy through the child's second birthday, and employs qualified well-trained nurses to provide ongoing home visits. Selected because of their training in health sciences, nurses follow manualised guidelines, visiting families weekly to biweekly for more than two years (Olds, Hill, Robinson, Song, & Little, 2000).

Rigorously evaluated through three randomised controlled trials in the USA (in Elmira, New York; Memphis, Tennessee; and Denver, Colorado), NFP has consistently improved outcomes for children and mothers across a variety of domains. In the Elmira trial, for example, women in the programmes smoked 25% less and had 75% fewer preterm deliveries than the control group. Over 15 years follow-up, they had fewer verified reports of child maltreatment and their children had fewer hospital visits related to child injuries or ingestion. Low-income unmarried mothers, in particular, had 33% fewer subsequent pregnancies, 30% fewer months on welfare and 69% fewer arrests (Olds et al., 2000). Overall, the benefits of the programme were greatest for families at higher risk and greatest when nurses rather than paraprofessionals were used as home visitors (Olds, 2006). Recognised as an evidence-based best practice, NFP has been replicated in 170 sites across the USA.

# The evidence for high-quality early childhood development (ECD) programmes

Generally targeted towards children and families living in poverty, ECD programmes are intended to counteract the factors that place low-income children at risk of poor outcomes. ECD programmes usually consist of multiple components, including early childhood education, health screenings and immunisation, nutritional support and parent education and homebased services.

To date, the strongest evidence for ECD programmes comes from high-quality model projects, such as the High/Scope Perry Preschool Project, the Abecedarian Carolina Project and the Chicago Child Parent Centers. Based in the USA, all three programmes included parent components and served disadvantaged, principally African-American, children. For each of these programmes, evaluation findings include a range of positive effects that have endured into adulthood, such as better academic achievement, educational progression and attainment (less grade repetition, higher graduation rates), labor market success as well as decreased involvement in crime and delinquency as compared with control or comparison groups (Barnett, 2007; Ou & Reynolds, 2006; Galinsky, 2006).

While none of these programmes have been replicated at a national scale, there are nonetheless useful lessons to be learned from the design of these interventions. Key components that contributed to their success include: they began early (either at birth or before the age of three); the teachers were well-educated, well-paid and well-trained; class sizes were small and teacher–child ratios were high; the programmes were intensive and included parents' education and support (Galinsky, 2006, pp. 19–22).

Of programmes rolled out to scale, Head Start and Early Head Start in the USA are the most promising models for high HIV prevalence countries. Both programmes specifically target low-income families and their children. Head Start is a preschool education programme for three and four-year olds which includes direct work with children, parent training and family economic and education supports. It also offers other services, such as health screening, immunization, nutrition support and family case management. While the evidence regarding programme effectiveness is mixed (Barnett, 1995; Currie & Thomas, 1995), a recent analysis argues that Head Start passes a benefit–cost test and can generate long-term benefits for participating children (Ludwig & Phillips, 2007).

Early Head Start builds on Head Start, but is specifically designed to serve pregnant women and families with infants and toddlers up to the age of three. Early Head Start programmes assume one of three models - home-based care (HBC), center-based care, or a combination of home and center-based ("mixed model") care. Early Head Start evaluation results demonstrated that programme children performed better than controls in cognitive and language development, displayed higher emotional engagement with their parents and were lower in aggressive behavior. In addition, compared with controls, Early Head Start parents were more supportive, provided more language and learning stimulation, read to their children more and spanked their children less. The strongest impacts were for programmes that offered a combination of center and home-based services (Love et al., 2005).

### Strengthening families through home visiting for first-time pregnant mothers and early childhood development (ECD) programmes

Not only do high-quality, well-implemented nurse home visiting and ECD programmes in the West improve outcomes for low-income children, they also provide essential supports to caregivers and help strengthen the capacity of families to care for their young children. Such programmes should be given consideration as strategies to strengthen families in the context of HIV, which can compromise parental care and create additional stress for low-income families.

Providing care for very young children is energy and time-intensive, especially, if a child or caregiver is HIV-positive and ill. Moreover, such interventions can ease the care burden on families affected by HIV/AIDS, in particular women and girls, who are carrying the preponderance of the care burden in high prevalence countries (cf. Lindsey, Hirshfield, Tiou, & Ncube, 2003; Ogden, Esim, & Grown, 2004). A heavy burden of care has implications not only for the mental health of caregivers (Orner, 2006), but also for the quality of care of young children in families affected by HIV/AIDS. A combination of home and center-based ECD programmes can ease the burden by enabling caregivers to take up other activities, such as income generation, schooling and self-care.

In SSA, where HIV is spreading predominantly through heterosexual transmission, HIV infection and pregnancy often converge. Sizable proportions of pregnant women in high-prevalence countries are also HIV-positive. In countries most affected, prevalence rates among pregnant women range between 20-40% (UNAIDS, 2006). Prevention of mother-tochild transmission (PMTCT) coverage rates, although improving, are still relatively low (less than 40%) in many high-prevalence countries in SSA (UNICEF, 2008, p. 29). Home-visiting programmes could play an important role both in terms of linking HIV-positive mothers to PMTCT services as well as strengthening prevention efforts to keep future generations HIVfree. Such interventions can also improve the health, care and treatment of young children, some of whom may be HIV-positive themselves. They can, for example, educate caregivers about how to provide optimal care for infected young children after birth, such as adopting safer infant feeding practices. Infant and under-five mortality rates are very high in SSA – 95 per 1000 live births and 160 per 1000 live births, respectively (UNICEF, 2008). There is thus a good case to be made for home visiting for low-income pregnant mothers as part of a comprehensive, integrated primary healthcare strategy to improve infant, child and maternal health.

Home-health visiting programmes could build upon existing structures of home-based care programmes in SSA, an established strategy for meeting the healthcare needs of people living with HIV and AIDS (PLWHAs).<sup>5</sup> However, it is important to note that the evidence on home visiting indicates that intensive, high-quality service is central to quality outcomes. The success of the NFP hinges, in part, on the use of nurses as home visitors. Given widespread human resource constraints in the public health sector throughout SSA, it is unlikely that homevisiting programmes in high-prevalence countries could rely primarily on nurses as home visitors. The key component is well-trained, well-qualified staff and there is certainly scope for assessing the effectiveness of trained and credentialed community health workers, who are paid salaries (as opposed to being volunteers or receiving stipends).

Scaling up high-quality ECD programmes in high-prevalence countries could also make significant contributions to strengthening families and positively impacting the life trajectories of impoverished children. Although the call to prioritise and expand ECD programmes in resource-constrained countries extends beyond the context of HIV/AIDS and is increasingly on the global agenda (cf. Engle et al., 2007), it has greater urgency in high-prevalence countries. Here previous gains in improving child health and development are being eroded by the epidemic.

### Conclusion

It is unquestionable that many families have responded with resourcefulness to the challenges presented by the HIV epidemic; yet the intersection of HIV/AIDS and poverty in high-prevalence countries also means that many impoverished families are struggling and require services and support. Evidence-based early childhood interventions supported by better infrastructure to deliver services can play a key role in offsetting some of the child and familylevel impacts of the epidemic. They can offer comprehensive family-centered services that address the interrelated caregiving, developmental, nutritional and healthcare needs of young children.

Certain caveats, however, are in order. Firstly, early intervention programmes should be seen as one important component of larger systematic efforts to strengthen public health, education and social welfare services in high-prevalence countries for all children. Secondly, while it is useful to learn from effective programmes from resource-rich countries, intervention strategies proven to work in these contexts require testing and modification through local effectiveness and implementation studies to assess their acceptability, feasibility and impact in impoverished high-prevalence contexts. Conditions vary significantly not only between resource-rich and resourceconstrained settings, but also across high-prevalence contexts.

Lastly, while early intervention programmes can provide necessary services to children and families, it will be difficult for families facing multiple stressors to benefit from interventions if they are struggling with the everyday realities of poverty. The implementation of family strengthening programmes thus must unfold alongside efforts to provide economic support to families.

#### Notes

 Given that there is considerable variation in family formations in terms of structure, residency and function, "family" is defined flexibly and understood in its broadest sense, as a social grouping and a social institution. It is understood that family members can be related through kinship (biological and social) and/or marriage, union, or other partnership arrangements.

- 2. Because few programmes specifically define themselves as "family strengthening", the defining criteria for inclusion were programmes that seek to enhance family functioning and/or outcomes for children through family-level interventions.
- 3. The present emphasis on early childhood in this article is not intended to discount the urgent need for large-scale evidence-based interventions with older children and their families in high-prevalence contexts. Unfortunately, the evidence on programmes to strengthen families directed towards older children and youth in high income countries is less established and also does not lend itself to application in high-prevalence countries (for further elaboration, see Chandan & Richter, 2008).
- 4. The term "children affected by AIDS" is an umbrella phrase which captures the diverse, often overlapping ways, children's lives have been and are being altered by the epidemic. These include being HIV-positive themselves, having mothers, fathers, or other caregivers who are HIV-positive, losing a parent(s) to AIDS, living in families that foster children affected by HIV/AIDS and/ or living in communities where large numbers of people are affected by HIV/AIDS (Sherr, 2005).
- Expanded within the context of the HIV epidemic, the reliance on home-based care is a response to the inability of public health services, particularly hospitals, to meet the care needs of increasing numbers of patients with AIDS-related illnesses (Campbell, 2004).

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