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## What's New in Research?

A review and analysis of recent publications on  
children affected by HIV and AIDS

February 2015 Edition

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*Funding was provided by the United States Agency for International Development (USAID) under Cooperative Agreement AID-OAA-A-11-00015. The contents are the responsibility of the Leadership, Management, and Governance Project and do not necessarily reflect the views of USAID or the United States Government.*

## What's New in Research?



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February 2015

PEPFAR partners with USAID's Leadership, Management, and Governance project to support the Human Sciences Research Council (HSRC), South Africa in the production of ***What's New in Research?*** - a quarterly newsletter that alerts readers to new scientific publications. The newsletter focuses on relevant, evidence-based applied science about children affected by HIV and AIDS, policy research, tests of effectiveness, rigorous program evaluation, and cost analysis. ***What's New in Research?*** is an initiative to make existing research more visible and accessible, and to encourage further research activities in the field of Orphans and Vulnerable Children.

In this issue, we review two papers on informal kinship fostering, a long-established tradition in Africa and now a key approach for responding to changing child care needs in the face of HIV and AIDS; two reviews, one on the psychological functioning of children exposed to HIV and the other on engaging fathers; one paper on depression and pregnancy, and one article on the development of children infected and affected by HIV.

### Reviewed in this edition of *What's New in Research?*

- **Informal kinship-based fostering around the world: Anthropological findings.**
- **They are not always a burden: Older people and child fostering in Uganda during the HIV epidemic.**
- **A systematic review of psychological functioning of children exposed to HIV: Using evidence to plan for tomorrow's HIV needs.**
- **Practitioner review: Engaging fathers - recommendations for a game change in parenting interventions based on a systematic review of the global evidence.**
- **Depression, pregnancy, and HIV: the case to strengthen mental health services for pregnant and post-partum women in sub-Saharan Africa.**
- **Child development in HIV-positive and HIV-affected children in South Africa and Malawi—What role for community organisations?**

## Informal kinship-based fostering around the world: Anthropological findings.

Leinaweaver, J. (2014). *Child Development Perspectives*, 8(3), 131-136. doi: 10.1111/cdep.12075

### Published Abstract

*Anthropological research around the world has documented informal, kinship-based foster care cross-culturally. In this article, I review some of the anthropological findings about the positive and negative characteristics of such arrangements. Research suggests that children are more likely to benefit from informal kinship-based fostering in cultural contexts where fostering expands the pool of relatives rather than substituting one parent for another, fostering is expected to provide children with positive opportunities for learning and development, or children are granted some autonomy or decision-making power. However, informal kinship-based fostering seems to place children at risk in cultural contexts where the process of children's attachment to caregivers resembles the Western model of child development, communities are highly stratified along socioeconomic lines, or exploiting children is permitted. I conclude the article by discussing implications for policy and research.*

Availability: <http://onlinelibrary.wiley.com/doi/10.1111/cdep.12075/pdf>

### Comment

The author cites several references indicating that informal care, including kinship-based fostering, is more common than institutionalization for the 163 million children worldwide estimated not to be living with a biological parent. Leinaweaver argues that such fostering is a viable option for the care of vulnerable children in cultural contexts where responsibility for children is spread across family and kin networks. Under these circumstances, in which kinship-based fostering is normalised, children can benefit from an expanded care system and increased opportunities for schooling. However, informal care puts children at risk when it jeopardises attachments; when foster children are treated differently from birth children, and when poor families place their children with wealthy relatives and the fostering takes the form of labour exploitation. Leinaweaver cautions, however, that not all of children's work in a household should be regarded in this way, as most societies have an expectation that children will contribute to the household economy in some way and children are expected to be responsible for household tasks.

### Implications for Policy and Practice

The author concludes that "Greater financial and social support for potential family caregivers of vulnerable children could help caregivers and protect children, not by removing them from kin who are actively engaged in their care, but by promoting fair treatment, education, and age-appropriate, kinship-appropriate tasks for such children" (p. 134).

**Box 1**

As defined by Groza et al (2011), quoted in the paper, informal kinship-based fostering is “the full-time care, nurturing, and protection of a child by someone other than a parent who is related to the child biologically, by legal family ties, or by a significant prior relationship” (p. 168). It does not involve formal adoption and child welfare professionals are not involved (thus it is distinguished from a foster care *system*).

**Reference:**

Groza V., Bunkers, K. & Gamer, G. (2011). Ideal components and current characteristics of alternative care options for children outside of parental care in low-resource settings. *Monographs of the Society for Research in Child Development*, 76, 163-189.

## They are not always a burden: Older people and child fostering in Uganda during the HIV epidemic.

Kasedde, S., Doyle, A. M., Seeley, J. A., & Ross, D. A. (2014). *Social Science & Medicine*, 113, 161-168. doi: 10.1016/j.socscimed.2014.05.002

### Published Abstract

*This qualitative study examines the role of older people (60 years and above) in fostering decisions for orphans and non-orphans within extended families in a rural Ugandan community heavily affected by HIV. Fieldwork conducted in 2006 provided information on the influence of HIV on fostering decisions through 48 individual in-depth interviews and two group interviews with foster-children and family members to develop detailed case studies related to 13 fostered adolescents. The adolescents included five non-orphans and eight orphans (five were double orphans because they had lost both parents). Older people play a very important role in fostering decisions as potential foster-parents, advisers, mediators and gatekeepers. They have a high level of authority over the foster-children, who are regarded as important resources within the extended family. With fewer potential caregivers available because of HIV-related deaths, the responsibility for fostering orphans has often fallen to surviving older people. Fostering is used by older people and the child's extended family as a strategy to ensure the welfare of the foster-child. When the foster-parent is an older person, it is also used to ensure physical and emotional support for the older person themselves. Support from the extended family towards foster households is widely reported to have been reduced by HIV by diminishing resources that would otherwise have been made available to support foster care. New initiatives and investment are required to complement community and family resources within well-managed social protection and welfare programmes. To be effective, such programmes will require adequate investment in administrative capacity and monitoring. They must aim to strengthen families and, recognizing that resources are limited, should prioritize the community's poorest households, rather than specifically targeting households with orphans or other foster-children.*

Availability: <http://www.sciencedirect.com/science/article/pii/S0277953614002895#>

### Comment

Again, the long-standing tradition of family-based fostering is asserted, arguing that it serves a number of purposes: education, care and socialization of children; ensuring reciprocity within families and, sometimes forgotten, providing companionship and assistance to aged relatives. In Uganda, approximately 19% of children do not live with their biological parents, and grandparents play an important role in this regard. Under patrilineal systems, children are usually cared for by the father's family but, in the case of orphans, children may also be taken in by the mother's family. The authors adopt a life course approach to their study, focusing on 4 themes: *linked lives*, or the way in which a person's relationships with others impacts health and welfare; *social timing*, for example, of fostering and the influence this has; *historical time* of an individual's life, and *human agency* or the degree to which a person can influence the course

their life takes. This qualitative study was nested within a much larger project to study household livelihood trajectories among 5,000 households from 25 villages. Among the findings were the following: 1) Although older caregivers did not always feel they had a choice but to take on fostering responsibilities, many held onto this role because they anticipated significant immediate and future benefits associated with fostering. In fact, “the importance of fostering as a means of ensuring continued care for relatives as they grew older was a recurrent theme in the dialogue with extended family members” (p. 165). 2) Fostering took a physical and financial toll on some older caregivers, and some received scant financial or material help, leaving them responsible for school fees and other expenses. Their sense of responsibility and conservatism associated with age resulted in them frequently restricting a child’s activities and contact with others. 3) Fostering functioned to protect children in the face of HIV, just as it had during the political and social turmoil of previous decades in Uganda. Older people have status in this respect and their guidance regarding fostering is sought. 4) While the system of family-based fostering is functional in rural areas, at least where families still have resources to share, it is not a realistic option for vulnerable families living in urban slums. 5) “Urgent efforts and investment are required to complement these community and family resources with comprehensive and well-managed social protection and welfare programmes” (p. 167).

### **Implications for Policy and Practice**

Both these papers substantiate that family fostering is normative in many countries hard hit by HIV, and that family fostering is the principle response of affected families to try and ensure continuity of children’s care and education. While many papers point to the potential risks associated with non-parental care, very few programmes to support family fostering for children have been systematically evaluated. As family fostering is the most sustainable and culturally acceptable strategy for caring for vulnerable children in Southern and Eastern Africa, more needs to be done urgently to develop and test models to support and strengthen family fostering.

## **A systematic review of psychological functioning of children exposed to HIV: Using evidence to plan for tomorrow's HIV needs.**

Sherr, L., Croome, N., Parra Castaneda, K., & Bradshaw, K. (2014). *AIDS and Behavior*, 18(11), 2059-2074. doi: 10.1007/s10461-014-0747-6

### **Published Abstract**

*Prevention of mother to child transmission of HIV can virtually eliminate paediatric HIV infection. Studies are needed to understand child development outcomes for children exposed to HIV in utero but born HIV negative (HIV affected children). This systematic review examined cognitive, developmental and behavioural outcomes for HIV affected children compared to control unexposed and uninfected children. Key word searches of electronic databases generated 1,739 hits and 11 studies with adequate quality design and measures of standardised cognitive, behavioural and developmental indices. Cognitive performance, behaviour and developmental delay were measured with 15 different standardised scales from 650 HIV affected children, 736 control children and 205 HIV positive children. Performance scores for HIV affected children were significantly lower than controls in at least one measure in 7/11 studies. An emerging pattern of delay seems apparent. HIV affected children will grow in number and their development needs to be monitored and provided for.*

*Availability: Subscription or pay for access*

### **Comment and Implications for Policy and Practice**

This is one in a series of systematic reviews conducted by Lorraine Sherr and her students, concentrating in this paper on the psychological functioning of children exposed to HIV (HIV-affected versus HIV-infected) in comparison to unexposed controls. The aim of the review was to narrow down the known adverse effects of being HIV-affected given that, with the expansion of PMTCT, the population of HIV-affected children will grow over time. The search was for studies with at least one measure of cognition, development or behaviour, and both samples of HIV exposed and unexposed children. Of the 11 studies identified, 6 were from Central Africa and the others from the United States, Asia and Europe. A wide range of developmental, behavioural and cognitive tests were used, including some non-standardized assessment procedures, and children ranged in age from 3 months to 24 years, which makes any conclusions from such diversity suggestive rather than conclusive. In addition, the studies were weakly designed – no study presented power calculations and sample sizes were generally very small, ranging from 20 to 234. There was variable availability of ART for adults, so children's exposure to the virus would also have been wide-ranging. The results, given the caveats listed, indicated that HIV-exposed children tended to have higher externalising behaviours (aggression, non-compliance etc) but with US children showing higher internalising scores (anxiety etc), and both developmental and cognitive measures indicated that HIV-exposed children had significant delays compared to unexposed controls. As the authors conclude, the "data is piecemeal with a variety of different indicators being used resulting in the inability to compare adequately across studies. It also brings up the complex debate on measurement

scales, validation and accuracy in various functional domains". Nonetheless, "this systematic review does point [out] that there is data, however tentative, that HIV-affected children are functioning below control children on a number of cognitive, behavioural and developmental parameters" (p. 2072). Little is known about the causal pathways beyond the fact that exposure to the virus, to ART treatment, and to chronically ill and potentially preoccupied parents may have adverse effects on children. In addition, women with HIV may themselves have been and continue to be exposed to risk factors which are known to affect child development, including substance abuse, transactional sex and exposure to intimate partner violence.



## Practitioner review: Engaging fathers - recommendations for a game change in parenting interventions based on a systematic review of the global evidence.

Panter-Brick, C., Burgess, A., Eggerman, M., McAllister, F., Pruett, K., & Leckman, J. F. (2014). *Journal of Child Psychology & Psychiatry*, 55(11), 1187-1212. doi: 10.1111/jcpp.12280

### Published Abstract

**Background:** *Despite robust evidence of fathers' impact on children and mothers, engaging with fathers is one of the least well-explored and articulated aspects of parenting interventions. It is therefore critical to evaluate implicit and explicit biases manifested in current approaches to research, intervention, and policy.*

**Methods:** *We conducted a systematic database and a thematic hand search of the global literature on parenting interventions. Studies were selected from Medline, Psychinfo, SSCI, and Cochrane databases, and from gray literature on parenting programs, using multiple search terms for parent, father, intervention, and evaluation. We tabulated single programs and undertook systematic quality coding to review the evidence base in terms of the scope and nature of data reporting.*

**Results:** *After screening 786 nonduplicate records, we identified 199 publications that presented evidence on father participation and impact in parenting interventions. With some notable exceptions, few interventions disaggregate 'father' or 'couple' effects in their evaluation, being mostly driven by a focus on the mother-child dyad. We identified seven key barriers to engaging fathers in parenting programs, pertaining to cultural, institutional, professional, operational, content, resource, and policy considerations in their design and delivery.*

**Conclusions:** *Barriers to engaging men as parents work against father inclusion as well as father retention, and undervalue coparenting as contrasted with mothering. Robust evaluations of father participation and father impact on child or family outcomes are stymied by the ways in which parenting interventions are currently designed, delivered, and evaluated. Three key priorities are to engage fathers and coparenting couples successfully, to disaggregate process and impact data by fathers, mothers, and coparents, and to pay greater attention to issues of reach, sustainability, cost, equity, and scale-up. Clarity of purpose with respect to gender-differentiated and coparenting issues in the design, delivery, and evaluation of parenting programs will constitute a game change in this field.*

Availability: <http://onlinelibrary.wiley.com/doi/10.1111/jcpp.12280/pdf>

### Comment and Implications for Policy and Practice

This important review proceeds from our knowledge that father involvement varies across cultures, social classes and situations, and has differential effects on children's developmental outcomes. Regardless of these variations, fathers have potentially important adverse and beneficial effects on children, mediated by social, psychological and biological factors. The

review identified only 14 prior intervention studies that included fathers, 11 of which were conducted in the United States, although more than 40 father-friendly or father-focused programmes have been identified. Among these, the evidence base is methodologically weak; few studies disaggregate findings by gender of the parent; most are limited to short-term, self-reported benefits which are known to be influenced by social desirability and, by and large, are limited to the global north. Programmes variously try to increase the amount of time fathers spend with children, their understanding of children's development, and their skills in child care and behaviour management, as well as reduce harsh parenting. More holistic programmes attempt to improve the quality of family life and satisfaction with the parental relationship. What has been found is that, regardless of whether fathers participate in parenting programmes or not, outcomes based on mothers' participation are better when there is another parent in the home. This global review identified 199 papers, of which 113 assessed a given father-inclusive parenting programme and 86 were reviews, commentaries, book chapters and working papers. There was only one programme from Africa, in Niger. Most interventions were aimed at primary prevention or harm reduction. In terms of programmes, there is little coherence with respect to how interventions are designed and quality varies, becoming increasingly weak in low and middle income countries. The authors conclude that an overhaul of programme delivery and design is needed to obtain the needed evidence on father engagement and father effectiveness.

**Box 2: A guide to best practices for building the evidence base of co-parenting interventions**

On page 20, the authors provide a guide, under the headings of *Design*, *Delivery* and *Evaluation*, to steer future interventions in a more useful direction. Two examples are given below:

*Design:* How attractive is the programme to co-parents? How culturally compelling is it?

*Delivery:* Does the timing, place and medium of delivery work to include fathers as well as mothers? Are sufficient resources committed to reaching both?

*Evaluation:* Does the reach of the intervention include all significant caregivers, including fathers?

*Design – Professional biases:* Do staff capabilities and attitudes towards parents include fathers?

*Delivery:* Are mothers and fathers explicitly informed and reminded about the importance of program participation and benefits to children? Are both parents followed up in cases on non-attendance? Are non-participating partners explicitly contacted?

*Evaluation:* Prevention and reduction of problematic outcomes related to quality of parenting and family functioning; child outcomes in health, education and psychosocial development; and maltreatment.

## Depression, pregnancy, and HIV: the case to strengthen mental health services for pregnant and post-partum women in sub-Saharan Africa.

Stringer, E. M., Meltzer-Brody, S., Kasaro, M., Stuebe, A. M., Wiegand, S., Paul, R., & Stringer, J. S. A. (2014). *The Lancet Psychiatry*, 1(2), 159-162. doi: [http://dx.doi.org/10.1016/S2215-0366\(14\)70273-1](http://dx.doi.org/10.1016/S2215-0366(14)70273-1)

**Published Abstract:** *This is a viewpoint*

*Availability: Subscription or pay for access.*

### Comment and Implications for Policy and Practice

In this viewpoint, the authors point out that widespread use of ARVs and PMTCT programs are decreasing infections and improving the lifespan of those infected, but that perinatal depression is endemic and is a serious threat to adherence. A recent systematic review in sub-Saharan Africa found that depression decreased adherence by half. Perinatal depression begins during pregnancy or within four weeks of giving birth, is substantially more common in low and middle income countries, and is highest in Southern Africa. The explanation for this variation in prevalence probably lies with increased risk factors in these regions – women are more likely to be affected by HIV, to have a child or spouse die unexpectedly, to live in poverty, and be exposed to intimate partner violence, conflict and trauma. Because perinatal depression affects the course of HIV as well as infant development through disturbed attachment, it is important both to screen for depression and treat it. Perinatal depression is treated by both psychotherapy and pharmacotherapy. Psychotherapeutic approaches, whether to improve interpersonal relations or to control thoughts and emotions that lead to maladaptive behaviour, can be delivered by trained non-professionals, such as peer mentors (for example, Rotheram-Borus et al, 2014). The authors conclude with the recommendation that counsellors and support groups in existing PMTCT programs be trained to incorporate screening and treatment for perinatal depression.

### Reference

Rotheram-Borus, M., Richter, L., van Heerden, A. et al (2014). A cluster randomised control trial evaluating the efficacy of peer mentors to support South African women living with HIV and their infants. *PloS One*, 9, e84867.

### **Box 3: Screening for perinatal depression**

The Edinburgh Postnatal Depression Scale is the most widely used and studied screening instrument. The scale consists of 10 questions, takes about 5 minutes to administer and can be self-administered or completed by a health worker. The EPDS has been validated against the gold standard of structured clinical interviews, including in South Africa and Zimbabwe (Rochat et al, 2013; Chibanda et al, 2010). A short (S, 4 items) and an ultra-short version (U-S, 3 items) have also been validated, as indicated below (Rochat et al, 2013).

1. Able to laugh and see the funny side of things
2. Looked forward with enjoyment to things (S, U-S)
3. Blamed myself unnecessarily for things
4. Anxious and worried for no good reason
5. Scared and panicky for no good reason
6. Things are getting on top of me
7. So unhappy I have had difficulty sleeping (S)
8. I have felt sad or miserable (S)
9. So unhappy I have been crying (S, U-S)
10. Thought of harming myself has occurred to me (S, U-S)

#### *References:*

Chibanda, D., Mangezi, W., Tshimanga, M. et al (2010). Validation of the Edinburgh Postnatal Depression Scale in a high HIV prevalence area in urban Zimbabwe. *Archives of Women's Mental Health*, 13, 201-206.

Rochat, T., Tomlinson, M., Newell, M-L. & Stein, A. (2013). Detection of antenatal depression in rural HIV-affected populations with short and ultra-short versions of the Edinburgh Postnatal Depression Scale (EPDS). *Archive of Women's Mental Health*, 16, 401-410.

## Child development in HIV-positive and HIV-affected children in South Africa and Malawi—What role for community organisations?

Skeen, S., Tomlinson, M., Macedo, A., Miltz, A., Croome, N., & Sherr, L. (2014). *Children and Youth Services Review*, 45(0), 90-97. doi: <http://dx.doi.org/10.1016/j.chidyouth.2014.03.041>

### Published Abstract

*There is evidence that children who are HIV positive (HIV +) are at risk for poor developmental outcomes. The aims of this study were to use developmental screening tools to measure outcomes of children affected by HIV/AIDS attending community-based organisations (CBO) and to determine what types of CBO provision these children were receiving. In a cross-sectional study, we interviewed 979 children and their carers (4 to 13 years) at 28 randomly selected CBOs funded by 11 major donors in South Africa and Malawi. Developmental outcomes were assessed using the Ten Questions childhood disability screening tool and the Strengths and Difficulties Questionnaire. Health-related quality of life was measured using the Paediatric Quality of Life Scale. Overall, 13.8% (n = 135) were HIV +. HIV + children were more likely to have developmental difficulties and lower health and educational quality of life, controlling for a range of factors. Developmental difficulties and poorer quality of life were predicted by being HIV +, living in South Africa, not attending school regularly, poor housing conditions and living with a sick family member. HIV + children tended to have been enrolled in CBO programmes for a longer period compared to other children but reported lower rates of contact. A greater proportion of HIV + children received medical services, psychosocial interventions and emotional support, compared to HIV – children. However, fewer HIV + children were enrolled in play groups, early childhood intervention programmes and educational programmes. Screening for developmental problems using short tools is possible in community settings in order to identify children with developmental difficulties and plan services for children infected with and affected by HIV. This study highlights the important role of CBOs to intervene to improve child development outcomes. The delivery of evidence-based services that target child development outcomes will enable HIV-infected children to meet their developmental potential and promote their participation in their communities.*

Availability: <http://www.sciencedirect.com/science/article/pii/S0190740914001479>

### Comment

This paper reports on what has come to be called “the community study”, led by Lorraine Sherr and Mark Tomlinson, and sponsored by the *Coalition for Children Affected by AIDS* and others. Several international NGOs are collaborating with the study to provide access to children and families served by their community programmes. In this study, the developmental outcomes of children infected and affected by HIV in South Africa and Malawi were compared. The HIV status of children was based on caregiver report, leaving some room for misclassification, and the range of ages of the children was wide, between 4 and 13 years of age. Children were also affected by HIV in various ways – 27% were double orphans, 22% were living with a sick adult,

19% had a caregiver who was HIV+, and 14% of children were confirmed seropositive. Nearly half of all children (43%) scored positive on the Ten Questions screening instrument for childhood disability, with HIV+ positive children having particular difficulty on items tapping motor development. Some of the results are difficult to explain – for example that children in South Africa tended to score lower on a number of the developmental assessments than children in Malawi, and the only robust predictor of children’s poor performance was not attending school, both of which may be attributable to underlying causal factors, either relating to the child (such as disability) or the environment (low levels of care and stimulation). A final critical finding is that HIV-affected, in comparison to the HIV-infected, children tended to be enrolled in CBO programmes for longer, to receive more frequent visits and other services, and to receive more psychosocial and emotional support services.

### **Implications for Policy and Practice**

The findings draw attention to two main policy and programme issues: First, that both HIV-infected and HIV-affected children and their families require services, and second, that greater attention needs to be given to ensuring regular, intensive services for HIV-positive children and their families. These children have known developmental risks, their families are HIV-affected, their adherence to ARVs needs to be maintained, and services must to be continuous to assist children and their caregivers to make a transition into adolescence that enables them to preserve their health and wellbeing, and adopt protective measures to prevent onward HIV infections.