

Children born into families affected by HIV

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The 2004 International AIDS Conference in Bangkok was the impetus for the formation of the Coalition for Children Affected by AIDS, formerly referred to as CCABA. Peter Laughan, currently the Director of the Firelight Foundation, drew like-minded people together in protest against the neglect of children in the HIV and AIDS response.

The present year marks the 10th anniversary of the Coalition, and this the third special journal supplement it has supported in the past decade. This supplement can be considered the fourth special supplement in a series, given that many people in the Coalition were also part of the Joint Learning Initiative on Children and AIDS (JLICA). JLICA Learning Group 1 produced a special supplement in *AIDS Care* in 2009 on ‘Strengthening Families’. This was followed by two special supplements in the *Journal of the International AIDS Society* (JIAS) coordinated and funded by the Coalition, one in 2010 on ‘Family-Centered Services for Children Affected by HIV and AIDS’, and the second in 2012 on ‘Community Action to End Paediatric HIV’. These special issues were launched at the Coalition’s Biennial Symposium on children’s issues, affiliated to the 2-yearly International AIDS Conference. This year the theme of the Coalition’s Symposium, hosted in collaboration with The Teresa Group and UNICEF, is ‘Children and HIV: Start Early, Start Now! - Integrated interventions for young children born into HIV-affected families’. The 2014 Symposium deals with many of the issues covered in this special supplement to *AIDS*.

Growing momentum on prevention of pediatric HIV infection, manifest in the Joint United Nations Programme on HIV/AIDS global plan to eliminate new infections among children [1], have brought successes. Between 2009 and 2012, new HIV infections among children dropped 35% and, between 2005 and 2012, nearly 1 million new HIV infections among children in low and middle-income countries were prevented [2]. However, despite measures to scale up programs for

treatment of pregnant women and prevention of mother-to-child transmission, a considerable number of HIV-infected pregnant women do not receive treatment; in 2012, only 37% of pregnant women in low and middle-income countries received antenatal HIV testing. This suboptimal coverage resulted in an estimated 260 000 children acquiring HIV during 2012, adding to the 3.3 million children under the age of 15 years living with HIV. HIV treatment for children (34%) continues to lag behind that of adults (64%) [2], and perinatally-infected children experience major health and adjustment challenges as they grow through adolescence into young adulthood [3]. Thus, the pediatric HIV epidemic is far from over.

The HIV epidemic continues to affect children who, though not infected themselves, have parents and/or other family members who are chronically ill or have died. This causes ripple effects in the lives of children, frequently leaving them distressed, poorer, stigmatized, prematurely out of school and responsible for livelihood and care, and potentially at increased risk of HIV infection as they enter adolescence. Some 17.8 million of the world’s children – 85% residing in sub-Saharan Africa – have lost one or both parents to AIDS [2]. Many times more children live with parents who do not know their HIV status, are ill with HIV disease, or are on lifelong treatment that may require onerous out-of-pocket expenses. This supplement addresses critical issues for all children born into families affected by HIV.

The first three papers are the product of a PEPFAR/USAID-funded process to synthesize the burgeoning research findings on the health, psychological and social effects of HIV on children [4]; use insights from the broader child development field to identify themes that are relevant to the long-term development of children affected by HIV, and that could help to predict long-term negative consequences for these children [5]; and in the absence of long-term studies, to draw on these insights to design models that incorporate multiple factors

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influencing child outcomes to estimate the magnitude of negative consequences of adult HIV infection on children, and to use these models to inform interventions [6].

The following 13 papers are arranged along a continuum of time and scale, from conception services through to parental disclosure to children, and from clinical trials to policy interventions. The final paper by Hsieh *et al.* [7] advocates for a reframing of the continuum of HIV care to include changing client circumstances and key moments of change that bring affected families into contact with supports beyond those offered by clinical services, such as networks of HIV-positive people, primary healthcare, and early child development services.

Despite a clear need for services to assist HIV-discordant couples who desire to have children through safer conception practices, limited services are available in high-burden settings, and a paucity of data on uptake and outcomes of such services in sub-Saharan Africa. Schwartz *et al.* [8] describe an implementation science approach to offering safer conception care in a primary health setting in South Africa, and demonstrate that such services can be feasibly offered in low-resource settings.

Breastfeeding by an HIV-infected mother is associated with the risk of HIV transmission to her infant, but because breastfeeding is the cornerstone of infant survival in low-resource countries, not breastfeeding brings considerable risk of mortality and morbidity to the HIV-exposed infant. Ciaranello *et al.* [9] model an evaluation of optimal infant feeding recommendations to maximize HIV-free survival among HIV-exposed, uninfected African infants. Their findings confirm that the current WHO public health approach toward infant feeding is beneficial in most resource-limited settings.

Over a period of evolving guidelines for care, Feinstein *et al.* [10] discuss the pediatric cascade of care in over 1700 mother–infant pairs enrolled in a family-centered comprehensive care clinic in Kinshasa, Democratic Republic of Congo, between 2007 and 2012. They note declines in both mother-to-child transmission and infant mortality, but continued problems with infant diagnosis and loss to follow-up, demonstrating areas in critical need of support to improve the overall outcome of children, their mothers and families.

Related to this finding, Finacchario-Kessler *et al.* [11] describe an innovative new HIV Infant Tracking System (HITS System) to improve the quality and efficiency of early infant diagnosis in resource-limited settings. This system uses an internet-based program accessible to team members at the hospital and laboratory, linking infant clinical and laboratory data, and includes text messaging

to mothers' mobile phones when test results are available, medical treatment is indicated or routine re-testing (e.g. at 9 and 18 months) is due. They found more than a two-fold increase in retention of infants in the early diagnosis cascade of testing as they aged, and in the initiation of antiretroviral therapy among HIV-infected infants compared to historical controls.

As antiretroviral therapy for pregnant and breastfeeding HIV-infected women dramatically increases with implementation of the new antiretroviral therapy guidelines [12], there are concerns about the effect of exposure of the fetus and infant to multiple antiretroviral drugs, though there is limited long-term follow-up data, particularly in resource-limited settings. Ngoma *et al.* [13] present data from a cohort study in Lusaka, Zambia, showing no evidence of adverse effects on neurocognitive and language evaluation among HIV-exposed uninfected infants subject to maternal antiretroviral therapy during pregnancy compared to control children born to HIV-uninfected mothers.

Disclosure of HIV status, both from mother to child, as well as from perinatally infected young people to others, is understudied. Rochat *et al.* [14] discuss the difficult problem of maternal disclosure of her HIV status to her primary school-aged uninfected children. Using a family-centered lay counselor intervention in South Africa, including home visits and child-friendly activities, they report that with limited structural support, mothers were willing and able to disclose their HIV status to their children. Evangelli and Foster [15] review the very limited research on HIV disclosure by HIV-infected children and youth to others, and emphasize the need for interventions to help perinatally-infected young people disclose their HIV status.

Two papers report on interventional studies. The first, from Eloff *et al.* [16] in South Africa, evaluated an intervention of 24 group sessions with mothers and their 6–10-year-old children, first separately and then together, to increase children's resilience. Although attendance was variable, children in the intervention group showed improvements in behavior, communication and daily living skills compared to children in the standard care condition. Betancourt *et al.* [17] report on piloting of a family-strengthening intervention in Rwanda for children 7–17 years of age to improve caregiver–child relationships, family communication and parenting skill through separate and shared group sessions, HIV psychoeducation and connections to resources. On the basis of good fidelity to the intervention, as well as participant and counselor satisfaction, it was concluded that the intervention was feasible and acceptable. Participants reported improvements in children's prosocial behavior, family connectedness, and good parenting, as well as decreases in harsh punishment, including at 6 months follow-up.

Two papers report on the role of perceived social support and the contribution of schools in supporting the well being of children 6–18 years of age in China and a large sample of similarly aged children in Zimbabwe [18,19]. The Chinese study, conducted in two rural areas with follow-up over 3 years, showed that children with higher baseline levels of child-reported psychosocial support reported lower levels of loneliness and higher self-esteem, leading the authors to recommend that interventions should target HIV-affected children with low levels of social support. In Zimbabwe, school quality was associated with the well being of primary, but not secondary, school children and with no additional benefits for vulnerable children. The well being of older children was found to be more responsive to community HIV prevalence.

In the penultimate paper, Cluver *et al.* [20] examine whether cash grants or integrated ‘cash plus care’ (comprising additional state and community provisions to mitigate poverty and disadvantage) reduce HIV-risk behaviors. In a follow-up study of more than 3500 South African young people 10–18 years of age, cash alone (in the form a universal social security grant) was found to reduce risk behaviors among girls, but not boys. However, integrated cash plus care was associated with a reduction by half in the incidence of HIV-risk behaviors among boys and girls, compared to no support and controlling for confounders.

The 16 papers in this supplement provide new data and new thinking across a wide range of issues pertaining to children infected and affected by HIV. In a discernible shift, the papers are focused more on potential solutions than on descriptions of problems. The value of the studies for improved implementation of effective interventions is enhanced by the fact that they are all situated in settings with the greatest challenges – areas with high HIV prevalence and low levels of resources.

Notable gaps, however, remain. For instance, between biomedical preventive approaches in pregnancy and early infancy on the one hand, and individual, family and structural interventions for affected school-aged children on the other, lies the critical period of early child development. As identified by Stein *et al.* [5], this is a time of increased environmental sensitivity, during which protection and care can both prevent children’s difficulties and ameliorate those that have already occurred. Another gap is a critical need for attention to the system demands for scale-up of interventions for children affected by HIV, as described in the study by Cluver *et al.* [20].

Enormous progress, however, has been made. There is global recognition of the need to prevent HIV among children; there is also increasing recognition that preventing HIV in pregnancy and infancy does not by itself reduce the risk of infection that affected children

face in adolescence. To address risk across the lifecycle requires that the policy, socioeconomic, environmental, cultural and interpersonal conditions that accelerate HIV infection are addressed through a combination of approaches that protect women, that support families and children, that bring effective and approachable services closer to those who need them, and that reduce discrimination, exclusion and violence throughout infancy, childhood and adolescence.

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Conflicts of interest

Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

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