



Now more than ever!

A need to reach the youngest children affected by HIV and AIDS

There is an urgent need to ensure that children affected by HIV and AIDS receive early integrated services to improve their long-term development.

- Only 39% of HIV exposed children are tested for HIV within two months of birth
- Too many children are lost in the gap between prevention of mother-to-child transmission (PMTCT) and orphans and vulnerable children programmes
- Children of the most stigmatised or most marginalised parents are too often overlooked
- Long-term benefits can be realised and we can stop and even reverse delays as early as possible

The years from birth to six present challenges as well as opportunities for HIV protection and risk mitigation. We know that HIV poses a biological risk for child development. However, the youngest children are too often missed in HIV testing and treatment efforts as well as in early learning programmes. In particular, those that are largely invisible and excluded from interventions such as children of sex workers, and of people who use drugs.

What is needed is an early, integrated approach. This will not only protect children but will also help them thrive. Decades of hard evidence, bolstered by groundbreaking neuroscience, prove the health, social and economic benefits of focusing on the early years.

To achieve this, an integrated package of services must be delivered across the health, HIV, education, early child development, protection and social welfare sectors. It ensures that children continue to be cared for starting from birth. Such an approach will, in the long run, be more efficient and cheaper.



Priority actions for early, integrated interventions

1. Implement early development programmes for the youngest children affected by HIV and AIDS
2. Integrate services for health, nutrition, HIV, parenting, economic support and early childhood development (ECD) for families affected by HIV
3. Keep children and families in care, don't lose them
4. Build capacities of families and communities to promote the development of children
5. Lobby government for policies and proper financing for early integrated interventions to be included in national plans and key sectoral ministries, e.g. education and health
6. Demand and support local health services to partner with community-based care, support and ECD services to reach the youngest children.



Why early intervention?

The early days of a child's life are crucial. Critical periods of the brain's development for vision, speech, hearing, language and cognition occur from birth to five years old. These set the stage for the future of children well into adulthood. We also know that children born into HIV-affected families face additional challenges that can impact on this development, e.g. antiretroviral therapies, physical and mental challenges, economic burden of HIV, and stigma amongst others.

Why integrated interventions?

Integrated interventions offer support to children and their families in a comprehensive way. They link services for health, HIV, child development and care and support, including family members or caretakers.

Integrated interventions can lead to better health for more children. For example by addressing early childhood development, health and nutrition within communities, more HIV-exposed children can be enrolled in HIV care. In addition, targeting HIV positive mothers in regular health services can ensure that their children have what they need to survive and thrive.

An early, integrated approach will, in the long-run, be more efficient and far cheaper. It will set the stage for a healthy development and life for children. Waiting for them to fall sick makes it much more difficult and costly to reverse the effects.



GOVERNMENT AND CIVIL SOCIETY PARTNERSHIPS

It is important that government officials and civil society are both actively involved in promoting ECD and early integrated interventions and work together to ensure:

- key sectoral ministries have ECD policies and joint planning and financing in place for early integrated interventions that benefit children
- evidence is compiled that shows investment in ECD leads to healthier communities and provides long-term economic benefits
- linkages are built between health systems and community-based programmes, e.g. child health days, referral systems, education and counselling volunteers at facilities.

Health, Early Childhood Development, and Care and Support: **three practical ways used to integrate services**

The current silos that exist between health, child development and HIV care and support services need to be broken down. Integration at both community and clinic levels can start with one entry point that other services are added on to. PMTCT services, for instance, present an ideal entry point for early identification of HIV-infected and -affected children, greater promotion of infant wellbeing, and prevention of loss to follow-up. But, there are many other opportunities to integrate services.

Promising approaches exist and need to be taken quickly to scale. A condition for successful scale-up is the training of community health workers, social workers and caregivers to provide integrated support. They need to be linked to existing health systems and recognised within it. In turn, health workers at facilities need to be trained to deliver integrated services, and work jointly at community level.

1. HEALTH SYSTEMS

To reach children and families in HIV prevention and risk mitigation, health services cannot work in isolation. They should have access to all relevant services on HIV, nutrition, health and development.

Health services need to:

- identify entry points to reach affected children from pre-natal to age six
- support the caregivers and identify other siblings in the household for care and support
- provide opportunities to address parenting and child development as part of maternal and child health services
- use both clinic and home visits to address multiple health and development issues.

CASE STUDY **Paediatric HIV services are integrated into nutritional programmes in Malawi**

Blessings Banda works as a nutrition and HIV coordinator for Abwenzi Pa Za Umoyo, a programme that combines HIV treatment with comprehensive, community-based health, integrating paediatric HIV services into nutritional

programmes. This integrated approach has led to an increase from five people on antiretroviral therapy in 2007 to an impressive 5,448 in 2013.

Blessings says, “I believe that the training of village health workers has been essential in ensuring this success. Community-based patients are more easily reached and at the same time we can address stigma”.



“We test all children under 12 years old entering the nutritional programme for HIV. All children under 24 months whose mothers are HIV positive are HIV-tested. We have improved malnutrition screening in both community and mobile HIV testing and counselling services.”

Blessings Banda sits with two-year old Rachel Namazongo who has been treated for malnutrition through the programme.

Additional reading: www.pih.org/blog/world-aids-day-malawi

CASE STUDY Combined clinic for HIV-exposed infants in Rwanda

John Wilson Niyigena works for Inshuti Mu Bushima in Rwanda. John says, "The combined clinic for HIV-exposed infants is a one-stop shop in which HIV positive mothers and their newborn infants can receive family planning, maternal and child health and PMTCT services in one place. This makes it easier for mothers to access services, which improves treatment adherence, reducing the transmission of HIV and maximising their infants' growth and development."

Between November 2010 and October 2012, Partners In Health supported 37 public health facilities to integrate services. John explains, "Through this approach we manage to test 99% of babies at six weeks for HIV. In the past two years we have served 973 mothers and their children in our clinics. And, we see an 18 months survival rate of over 97% at Partners In Health-supported clinics compared to 93% nationally."

Additional reading: www.pih.org/blog/combined-clinics-help-combat-mother-to-child-hiv-transmission and www.pih.org/blog/how-rwanda-is-redefining-hiv-care-for-the-worlds-poor

2. EARLY CHILDHOOD DEVELOPMENT

Early childhood is a time of rapid biological development. It provides strong foundations for physical, mental, social and emotional development. The impacts of parental illness and death, economic hardship, social exclusion as well as the potential impacts of HIV exposure to brain development can negatively affect young children. ECD services may be delivered both formally by governments and informally via the efforts of communities and civil society organisations.

Service providers need to:

- provide protective and nurturing environments to maximise children's development
- support the child and caregiver relationship in home settings to provide entry points to other services
- use pre-school centres to reach both children and caregivers with a range of needed services
- design ways to address the specific development needs for HIV-affected children and families
- introduce awareness raising on HIV into their family support programmes.

CASE STUDY Early childhood development centres act as entry points to reach children affected by HIV in Zambia

Grace Mazala works for Episcopal Relief & Development, in partnership with the Zambian Anglican Council. Grace says, "Our Early Childhood Development Programme has established 53 community-based early childhood centres in three

provinces that support the cognitive, emotional and physical development of children. As well, we offer a wide range of services including HIV, child health, nutrition and economic security."

Over 770 volunteers and 270 professional ECD workers have been trained. There is long-term commitment to scale up this work within seven provinces in Zambia, thereby reaching 12,000 children 7,070 caregivers and their families.



"We reach over 8,000 children and their caretakers at our centres on monthly basis. We provide advice and skills through support groups. In addition we visit 5,000 households monthly to ensure that vulnerable families are connected to needed services. Linkages with the Ministry of Health mean that HIV testing, counselling and referrals are available periodically at the ECD centre as well as growth monitoring."

Additional reading: www.ccaba.org/wp-content/uploads/Mazala-Grace-Presentation.pdf and www.ccaba.org/wp-content/uploads/Mazala-Grace-Poster.pdf

CASE STUDY Child Health Days in Malawi

Catholic Relief Services hold Child Health Days to focus on integrated early childhood care and development for HIV affected communities. Fidelis Chasukwa, who coordinates the Child Health Days, explains, “The day offers growth and development monitoring, HIV testing, screening and treatment for common health issues, immunisation, nutritional support and family counselling. With five Child Health Days carried out in 2013, we managed to reach 1,323

children and their caregivers. In addition, these days build informal linkages and referral networks around child health development and welfare in communities.”

The success of the approach is based on the early childhood education centre acting as a hub for children’s services, offering referrals for a full range of services for the youngest children. The days also provide opportunities to bring different services providers together.

Additional reading: www.crsprogramquality.org/storage/pubs/education/child-health-days.pdf

3. CARE AND SUPPORT

Many programmes targeting orphans and vulnerable children see children too late, missing the earliest years. Only a few of these programmes link with services that could provide an early, ‘all-in’ approach for young children and their families.

Care and support systems for orphans and vulnerable children need to:

- ensure access to health services that include HIV testing and treatment as early as possible
- make strategic links with HIV services, such as PMTCT, to identify the most vulnerable families before they are affected by HIV
- provide opportunities for the integration of early childhood development interventions within the programmes they have.

CASE STUDY Integrated early childhood development and HIV programmes in Mozambique

PATH has adapted existing materials for working with vulnerable caregivers and children from pregnancy to five years. In Mozambique, PATH with support of Hilton Foundation and BHP Billiton, has trained community-based organisation volunteers, community health workers and maternal and child health nurses.

Caregiver behaviour change is supported with tools such as a home visit planning tool, counselling steps cards and a supervision tool. Health workers are encouraged to work with the whole family and to help link families with relevant stakeholders to address any needs beyond the project scope.

By promoting links between community-based organisations and other stakeholders at the community level, many new cases of HIV-affected families and specific issues, such as serious developmental delays, malnutrition and domestic abuse, have been identified and referred. Some of the changes include: caregivers starting to talk and play with their children in the first months of life; use of daily routines and chores as opportunities for play; and greater use of positive discipline practices.



Health workers provide advice on early childhood development.

Advocating for integrated interventions

The following five steps are for undertaking advocacy aimed at strengthening integrated interventions for young children born into HIV-affected families. These steps could be undertaken by civil society at local, district and national levels.



Step 1: Undertake a mapping exercise

Map the key stakeholders, the policies and strategies that exist on early interventions for children. Record the progress in implementing these policies, and the required activities to address the identified gaps.



Step 2: Prepare a strategy to lobby government to design and implement policy commitments

Develop and disseminate messages about the importance of early integrated interventions for young children born into HIV-affected families. Hold meetings with relevant policy- and decision-makers to discuss how to implement the recommendations.



Step 3: Monitor what is happening

Monitor if stakeholders are delivering on their commitments, especially at community and district levels.



Step 4: Identify challenges to implementation and advocate for your solutions

Analyse the actions taken by the main stakeholders, note any delays and identify the causes that need to be discussed with key stakeholders to identify solutions.



Step 5: Undertake an annual review

Each year review progress made on each of the action points in the strategy and decide whether additional steps are needed.



CASE STUDY

Successful advocacy on early, integrated interventions in Kenya

Teresia Otieno from the National Empowerment Network of People Living with HIV in Kenya (NEPHAK) participated in the first Road to Melbourne meeting led by the Coalition for Children Affected by AIDS in New York and gave a presentation on community engagement to prevent mother-to-child transmission.

"I was struck by the other presentations, specifically on how interventions are being done in

isolation and how early childhood is being left out of the response to HIV.

Upon my return to Kenya, I made a deputation to members of the Parliamentary Committee on Health and spoke about integration of different sectors including ECD into the PMTCT and nutrition agendas. As a result, I now represent women living with HIV on the national Technical Working Group on PMTCT and on the National Steering Committee for the Beyond Zero Campaign Initiative led by the First Lady of Kenya."

Additional reading: <http://beyondzero.or.ke>



The Coalition
for Children
Affected by
AIDS

For more information see www.ccaba.org/resources

The Coalition for Children Affected by AIDS believes that children need to be made a higher priority in the international response to HIV and AIDS. We bring funders and technical experts together to advocate for the best policy, research and programmes for children because children are a vulnerable population that has too often been overlooked.