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Coordinating Comprehensive Care for Children



# **SUMMARY OF KEY APPROACHES ON IMPROVING HIV TESTING AND SERVICES FOR CHILDREN ORPHANED OR MADE VULNERABLE BY HIV (OVC)**

Expanded IMPACT Program in Zimbabwe  
Lea Toto and APHIAplus *Nuru ya Bonde* programs in Kenya  
Yekokeb Berhan Program for Highly Vulnerable Children in Ethiopia

*This publication is made possible by the generous support of the American people through the United States President's Emergency Plan for AIDS Relief (PEPFAR) and the United States Agency for International Development (USAID) under cooperative agreement AID-OAA-A-14-00061. The contents are the responsibility of the Coordinating Comprehensive Care for Children (4Children) project and do not necessarily reflect the views of USAID or the United States Government.*

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## Acknowledgements

4Children staff and consultants are very grateful for the generous collaboration of the World Education Inc./ Bantwana team in Zimbabwe, the Yekokeb Berhan team in Ethiopia and the Lea Toto and APHIAplus *Nuru ya Bonde* teams in Kenya, and the government counterparts in Zimbabwe, Ethiopia and Kenya. In addition, many thanks to the numerous caregivers, community volunteers, program staff from implementing partners and other representatives from government and civil society supporting these HIV services for children who generously shared information and experiences that helped to inform the case studies.

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## Acronyms

<b>AIDS</b>	Acquired Immune Deficiency Syndrome	<b>OVC</b>	Orphans and Vulnerable Children
<b>ART</b>	Antiretroviral Therapy	<b>PEPFAR</b>	U.S. President’s Emergency Plan for AIDS Relief
<b>CC</b>	Community Cadre	<b>PITC</b>	Provider Initiated Testing and Counseling
<b>DHS</b>	Demographic and Health Survey	<b>PLHIV</b>	People Living with HIV
<b>EIP</b>	Expanded IMPACT Program	<b>PMTCT</b>	Prevention of Mother-to-Child Transmission
<b>GBV</b>	Gender-based Violence	<b>RBF</b>	Results-based Financing
<b>HEW</b>	Health Extension Worker	<b>UNAIDS</b>	The Joint United Nations Programme on HIV/AIDS
<b>HIV</b>	Human Immunodeficiency Virus	<b>USAID</b>	United States Agency for International Development
<b>HTS</b>	HIV Testing and Services	<b>USD</b>	United States Dollar
<b>NGO</b>	Non-government Organization		
<b>OHA</b>	Office of HIV and AIDS		
<b>OLMIS</b>	OVC Longitudinal Management Information System		

## Purpose of the HIV Testing and Services (HTS) Case Studies

In spite of the dramatic success of HIV treatment programs around the world, children remain under-represented in HIV testing numbers, and are thus denied access to lifesaving treatment. The [UNAIDS 2015 Progress Report](#) states that in 2014, only 49% of all HIV-exposed infants in the Global Plan's 21 priority countries (see sidebar) received a virologic test to determine their HIV status within the first two months of life, as recommended by the World Health Organization.

*Improved case finding of HIV-infected infants, children and adolescents is urgently needed to maximize pediatric treatment coverage, reduce rates of HIV-related infant and child mortality, and optimize outcomes and prevent future spread as children mature to adulthood.*

The same report reveals that only 31% of children living with HIV were receiving the antiretroviral treatment they needed.<sup>1</sup>

Childhood HIV infection is especially complex in terms of case finding, diagnosis and treatment — requiring specific approaches dependent on whether infection was vertically or horizontally acquired — and whether it is suspected at birth, during early or middle childhood, or

adolescence. Like adults with HIV, children and adolescents living with HIV face a multitude of practical barriers (see Annex 1) in achieving viral suppression, but they are perhaps even *more* constrained as they are subject not only to the wide range of household-level, developmental and societal barriers, but also by their reliance on caregivers.

Programs for orphans and vulnerable children (OVC), through their community presence and unique relationships with caregivers and children, are especially well placed to promote and facilitate the entire HIV care and treatment cascade over time with age-appropriate information and approaches. The programs have a long history of building community capacity to protect children through awareness and self-management of child protection threats and solutions, increased male involvement in parenting and child health, reducing stigma and discrimination, and providing a range of social supports to children living with HIV and their families.

Acknowledging that OVC are at increased risk for HIV<sup>2</sup> infection, and in alignment with PEPFAR technical guidance,

### Global Plan's 21 Priority Countries

Angola	Ethiopia	Nigeria
Botswana	Ghana	South Africa
Burundi	Kenya	Swaziland
Cameroon	Lesotho	Tanzania
Chad	Malawi	Uganda
Côte d'Ivoire	Mozambique	Zambia
DR of Congo	Namibia	Zimbabwe

OVC programs aspire to ensure that all individually registered OVC beneficiaries have a known HIV status. Over the past four years, many programs have scaled up efforts to apply family-centered approaches to promote and facilitate testing, treatment linkages and adherence support for children and adolescents, while encouraging other household members, including fathers, to also know their HIV status and access relevant treatment and other services.

In response to a request from the Office of HIV and AIDS (OHA) at USAID, 4Children was asked to develop a set of case studies to promote learning from OVC programs that have successfully designed interventions and approaches to increase HTS for children.

### SELECTION OF THE CASE STUDIES

Three countries were identified by OHA including Ethiopia, Kenya and Zimbabwe. Between April and September 2016, 4Children conducted field visits and documented OVC programs in these countries; the programs included COGRI's Lea Toto program and FHI360 led APHIAplus program in Kenya, the World Education Inc./Bantwana Expanded IMPACT Program (EIP) in Zimbabwe and Pact's Yekokeb Berhan program for highly vulnerable children in Ethiopia.

### METHODOLOGY

A team of two consultants with expertise in OVC and HIV programming conducted the case studies with support from 4Children's Technical Director for Child Protection and Welfare Systems. A significant desk review was also conducted prior to the fieldwork, and included project-level, country-specific and global-reference documents. One of the consultants spent one week in both Ethiopia and Zimbabwe, and two weeks in Kenya. The field visits included key informant interviews with USAID technical staff, implementing partners, government and health sector staff, community leaders and volunteers, caregivers and adolescents living with HIV. Across the three countries, more than 230 people participated in key informant interviews and focus group discussions. The process of developing the case studies provided a unique opportunity to not only highlight the positive approaches and results of increased HTS within OVC programming, but also to illuminate the continuing challenges faced by OVC in their efforts to contribute to the 90-90-90 goals.

### HIV Testing and Services (HTS) within OVC Programming

The following report summarizes the strengths, challenges, lessons learned and remaining gaps of the Lea Toto and APHIAplus programs in Kenya, the Yekokeb Berhan Project in Ethiopia and the EIP in Zimbabwe. Specifically, this report documents each program's efforts to a) test 100% of HIV-exposed infants, children and adolescents, and promptly treat those with vertically acquired infection, and b) identify all children ages newborn to 17 years with acquired HIV infection, and link them promptly to care and treatment.<sup>3</sup> To achieve this requires an "all-hands-on-deck" approach to building awareness about — and facilitating access to — HIV testing of children, helping parents and caregivers overcome fears and resistance to child testing, assisting

with age-appropriate disclosure and information-sharing, and supporting access to appropriate treatment. Balanced, inclusive and ethical approaches that mitigate the potential for harm, stigma and discrimination of children and families affected by HIV, AIDS and other adversities are critical.

This report is intended for program designers, managers and practitioners, with the aim of helping them to better understand how OVC programs can be designed to effectively address existing barriers, and enable vulnerable children to access the HTS they need. It also highlights several challenges that require urgent, collective action to ensure these especially vulnerable children and their families receive the lifesaving services they need.

## Barriers to HTS for children

Through the process of conducting field visits to the three countries, as well as through a review of relevant literature (see Annex), 4Children identified and prioritized the following barriers to the uptake of HIV testing and effective linkage to treatment. These barriers were the most prominent across the three case study countries, and resonated strongly with the literature.

*In Ethiopia, case study respondents all mentioned fear of stigma and discrimination of their children as one of the most important deterrents to HIV testing. In Kenya, respondents shared that mothers are often reluctant to discover their own HIV status due to fear of beating and abandonment by their partners, separation from other children and shaming in front of family and friends. In Zimbabwe, fear of the blame and terrible shame associated with one's child being infected with a sexually transmitted disease prevents caregivers from considering HIV, even when the child is ill. This suspicion is especially easy to deny when the child is not visibly ill.*

**HIV among children is poorly understood, and children living with HIV are especially vulnerable to stigma and discrimination.** Fear around HIV-related stigma and discrimination remains a formidable challenge, hindering access to accurate information and services. The mutually reinforcing triad of denial, misinformation and stigma are significant constraints to both information sharing and care-seeking behavior.

Fear of stigma and rejection can also be heightened in situations where the burden of care is on women, and men are not engaged. Family and cultural norms, such as household power dynamics and gender-based violence, can deter female caregivers from acting on the child's behalf if a child's status could result in "punishment" of the mother. Equally, dread and shame are often related to a positive test result for older children due to the assumption (however incorrect) that the child has been sexually active.

*HTS services for children in Ethiopia are severely constrained by the strict interpretation of the Ministry of Health's confidentiality policy that prohibits health care providers from disclosing a client's HIV status to community volunteers or program staff. Health facilities are not always willing to confirm whether referred caregivers or children even presented for or received HIV testing services, and none will provide information on whether a client was linked with HIV treatment. In Zimbabwe, locating OVC services within the social sector and HIV services within the health sector—and failing to create practical bridges to link the two service areas—have perpetuated barriers to HIV prevention, timely case detection, service access and retention in care.*

**Over-reliance on clinical providers, exclusion of community-based workers from health-related "confidential" information, and structural barriers between the health and social welfare sectors** impede early identification of HIV infection and the delivery of holistic care for children and their families. Operationalizing case management depends on a "one team" approach that includes informed, HIV-literate community volunteers to provide support at household level. Facility-based provider-initiated testing and counseling (PITC) depends heavily on the presentation of illness to prompt HIV testing.<sup>4,5</sup> While active referral of HIV-infected parents engaged in care can greatly improve testing uptake and yield, and identifies children prior to serious illness, the vast majority of parents still decline testing for their children.<sup>6</sup> Community volunteers are essential to the effective promotion of HTS, but they are often denied access to the "confidential" information that underpins a productive relationship with the client and the delivery of fully integrated care.

**The identification of infection in older children and adolescents is not sufficiently prioritized.** It is now understood that about a third of HIV-infected infants have slow-progressing disease, thus substantial numbers of children in sub-Saharan Africa with perinatally acquired HIV have been presenting to health care services for the first time during adolescence.<sup>7</sup> In addition, the needs of sexually active adolescents, early married girls, schoolgirls with "sugar daddies" and survivors of sexual and gender based violence are not consistently or specifically addressed in community-based OVC programs, and screening algorithms that apply to at-risk adolescents are not widely used by clinical or community providers.<sup>8</sup> This was the case in every program studied.

Finally, **policies and protocols governing consent can serve as impediments** to HTS, specifically with regard to adolescents and their need for privacy and to children without a designated guardian, or those unable to obtain consent from unwilling or absent parents where there is rarely a "Plan B" that provides for a proxy guardian.

**Lack of clarity about optimal timing and process pose barriers to disclosure of HIV status to children** and result in low rates of disclosure, particularly in resource-limited

*In Zimbabwe, a large number of children are not living with their birth parents: almost one-third of all households are caring for foster children, i.e., their parents are alive, but the children are living in a household where neither biological parent resides. According to the Zimbabwe DHS 2010-11, 9% of households are caring for double orphans, and 19.5% are caring for single orphans. These children face specific legal barriers to accessing HIV testing services as, in most cases, the children are neither formally adopted nor fostered, and therefore their caregivers do not have the authority to legally provide consent for testing.*

settings.<sup>9,10,11,12,13,14</sup> Parents, caregivers and service providers at all levels are generally reluctant to inform a child of her/his HIV status, and often delay in initiating discussion. There is increasing evidence that disclosure plays an important role in improving medication adherence and HIV-related outcomes.<sup>15,16</sup> While several studies show that children reported feeling sadness, grief and worry upon learning about their HIV infection, these negative feelings were often followed by a sense of relief and purpose.<sup>17</sup>

**The shortage or rationing of HIV test kits and services is a critical constraint** for OVC and prevention of mother-to-child transmission (PMTCT) programs in many countries.<sup>18,19</sup> This was particularly evident in Ethiopia.

**Distance to testing and treatment services for children also continues to be a barrier.**<sup>20,21,22</sup> Decentralized models for health and HIV care are gradually increasing access in many rural settings, with demonstrated success. However, caregivers still report problems accessing clinics, most often due to lack of money, transportation and poor road conditions, especially during the rainy season. In addition, lack of trained staff and erratic availability of pediatric formulations in rural clinics can delay linkage to treatment because of long distances to referral hospitals.

*In Kenya, interviews with children, community volunteers and HTS providers revealed that delays in initiating this important conversation caused confusion, mistrust and anger among children. Adolescents interviewed described caregivers side-stepping their direct questions, providing incorrect information (intentionally or unintentionally), or otherwise handling disclosure poorly. In response, they became rebellious, secretive, depressed and suicidal, and in many cases expressed this by finding ways not to adhere to treatment.*

## Strengths and successes

Across the four programs studied, important strengths and successes were identified in terms of addressing the above described barriers.

## PLHIV ENGAGEMENT IS CRUCIAL TO OVERCOMING BARRIERS

Case study respondents in all three countries reaffirmed that the engagement of people living with HIV (PLHIV) is crucial to help clients overcome denial, misinformation and fear of stigma. While HIV status was never a requirement to become a volunteer, encouraging those with prior HIV caregiving experience naturally resulted in employing many HIV-positive OVC volunteers and caregivers of children with HIV. Their ability to use their own experiences and carefully timed disclosure of HIV status and personal experiences is often critical in convincing parents and caregivers to overcome fear and denial, and access HTS for their child(ren).

## LARGE, MULTISECTORAL OVC PROGRAMS CAN TACKLE HIV BARRIERS WITHOUT STIGMATIZING INDIVIDUAL CHILDREN

In Ethiopia, a country with a larger population but lower HIV prevalence than the other two countries studied, the Yekokeb Berhan program focused on geographic areas with highest prevalence (urban and semi-urban areas), and employed a non-stigmatizing community-based approach to identify and enroll children at risk of HIV. The program engaged existing community structures in the identification of *all* vulnerable children, and deliberately affiliated the OVC program with the widely accepted national health extension program. Using a well-trained cadre of volunteers armed with relevant assessment and counseling tools, the program gained intimate access to each household, and was able to zero in on the children most in need of HIV services.

## HEALTH AND SOCIAL SERVICES, WORKING TOGETHER, ADDRESS BARRIERS MORE EFFECTIVELY

All four programs developed **strategies to bridge divides between the health and social welfare sectors and address the challenges of siloed service provision.**

*In Zimbabwe, the EIP started by leveraging complementary funding that allowed the project to work across the two sectors through one holistic approach. This funding stream allowed the program to create a staff team that reflected the complementary skills sets of both the health and social welfare sectors. They deliberately recruited “health” volunteers (village health workers, home-based care providers, mentor mothers and male mobilizers) into the OVC volunteer workforce, and leveraged their years of HIV training, experience and relationships. Simultaneously, they brought HIV literacy to the social welfare (OVC) volunteer cadre to ensure the swift identification and response to the combined vulnerabilities of child protection violations and HIV. This bridging of services enabled the various cadres to work together to find solutions in complex situations, such as gaining consent for a child who is living with extended family or an unrelated adult. The EIP extended the reach of HTS services for children even further by partnering with the education sector to use school health assessments and adolescent health fairs as platforms to normalize HIV testing for children, and remove access barriers.*

*In Ethiopia, Yekokeb Berhan created a workforce of HIV-literate community volunteers to actively promote HIV testing*



and remove barriers to testing and treatment for children and their families. The program demonstrated that volunteers are able to serve both the health care and social welfare systems simultaneously and effectively. Significantly, the program's volunteers brought added value through having one foot in the child protection/social welfare camp, and used their training to identify and intervene appropriately when a child with HIV might be neglected, scapegoated, bullied or otherwise abused.

*In Kenya*, both programs demonstrated that building in social work capacity adds value by protecting health sector investments over the long-term. The observations drawn during case study interviews revealed a clear advantage for programs that employ social workers relative to those that do not. Social workers, by virtue of their professional orientation, are sensitive to the specific issues experienced by children with HIV, and are able to anticipate the support they might require. They are attuned to the subtle clues that indicate child distress, and are able to provide age-appropriate assistance. They also benefit from collegial connections with relevant service providers, such as adolescent psychologists, GBV service providers and child protection offices. All of these inputs aim to improve psychosocial health, adjustment to disclosure, commitment to positive living and improved treatment adherence. Similarly, they have demonstrated that bringing OVC literacy to community health volunteers ensures the swift identification and response to the combined vulnerabilities of child protection violations and HIV. This expertise was inculcated by the deliberate recruitment of social services staff to support and manage the community volunteer cadre.

### A "ONE TEAM" APPROACH DELIVERS STREAMLINED, HOLISTIC CARE

The case studies provide successful examples of how to increase collaboration between community volunteers and health professionals, and help them work together in a team.

*In Zimbabwe*, to increase collaboration between facility- and community-based team members, the EIP initiated case management meetings held at the health facility (rather than in the community), which enabled the nurse to more easily attend and provide input and leadership and receive referrals. *In Ethiopia*, the community volunteer workforce directly assists health extension workers (HEWs) to fulfill their roles, especially with regard to promoting HIV testing. With the support of the volunteers, HEWs are able to function more effectively as the "hub" for health-related case management, while community volunteers serve as a de facto "development army."

*In Kenya*, Lea Toto and APHIAplus program volunteers are trusted members of the HIV care and treatment team, clearly demonstrating a "one team" approach to client care. The mutual respect between the Lea Toto and APHIAplus program volunteers and clinical health care workers allows them to assist and support clients, while respecting confidentiality. In both programs, respect for confidentiality of the client's status is at the core of winning clients' trust. In APHIAplus, clients provide formal consent during program enrollment, allowing the program to track each client's status. In Lea Toto, the HTS

counselor obtains verbal consent. In both cases, agreement is obtained from the client in a straightforward manner

### SUPPORTING GOVERNMENT LEADERSHIP AND BUILDING ON EXISTING STRUCTURES LENDS CREDIBILITY AND PROMOTES SUSTAINABILITY

All four programs have demonstrated a clear commitment to supporting government leadership, linking with well-accepted national programs (such as the health extension program in Ethiopia), adhering to government guidelines, and engaging government trainers to provide training. The fact that these programs are so clearly guided by government strategies and nested in the government's response to HIV gives them credibility, enables them to adapt rapidly to updated government guidelines, and makes it possible for program approaches to be adopted by existing services and structures, and thus facilitating their sustainability.

### OTHER IMPORTANT INITIATIVES

The Yekokeb Berhan program should be commended for their efforts to help OVC and caregivers access HTS despite the shortage of HIV test kits. This includes the leveraging of corporate social responsibility of private clinics, and forging partnerships with NGOs to provide free-of-charge HTS to OVC and their caregivers, and their successful joint advocacy with other stakeholders in the HIV response against a recent, short-lived government requirement that user fees be charged for HTS.

Other important initiatives include the use of Results-based Financing (RBF) indicators in Zimbabwe to incentivize child testing and treatment initiation, providing health facilities ten cents for every child tested for HIV, and five USD for every seropositive child initiated on treatment. Through their own improved performance on the new pediatric HIV testing and treatment indicators (in addition to several other RBF indicators), primary health facilities are better able to cover their operating costs. During the case study discussions with health staff, it was clear that this financial incentive effectively influences provision of HIV testing. In Kenya, the development of a user-friendly data management system and linking of adherence support with viral load monitoring are potential game changers. Kenya's OVC Longitudinal Management Information System (OLMIS) stands out for its user-friendliness, and for the quality and completeness of the data it generates. It enables rapid monitoring and follow-up of a child's status by the multidisciplinary team supporting the child and family. The APHIAplus mechanism for merging adherence monitoring (through home-based observations and tracking of clinic attendance) with viral load test results has potentially both lifesaving and cost-saving impacts. APHIAplus has demonstrated that through establishing relationships that allow for sharing of relevant information, it is possible to monitor the progress of each child on treatment *at scale*.

### Gaps and challenges

In addition to the shared successes across programs, there were also common gaps and challenges that occurred across the different contexts.

## LACK OF GUIDANCE TO SUPPORT OPTIMAL DISCLOSURE TO CHILDREN

There is an urgent need for evidence-based guidance around the process and timing of disclosure to children, including indicators of child readiness and age-appropriate techniques and language. This is a crucial element in forging and sustaining a successful link to treatment. There is no clear understanding around the different roles of the caregiver, the community volunteer and the clinical service provider in this process. “Doing it right” is crucial not only to the psychosocial health of children, their treatment adherence and the maintenance of family integrity, but also to preventing onward transmission as expanding numbers of children with HIV mature to adolescence and become sexually active. Volunteers and clinical staff need to feel confident about initiating and guiding age-appropriate conversations, as well as providing information that is both sensitive and technical. The evidence base for the development of guidance, curricula and tools is thin at best.

## LACK OF EVIDENCE ON EFFECTIVE APPROACHES TO SUPPORT TO CHILDREN AND ADOLESCENTS WITH HIV

Evidence around the effectiveness of the various support group formats and methodologies for children and adolescents is needed to underpin clear guidance, tools and training materials, and a secure resource stream. While youth activists for HIV prevention have been very influential in the past two decades, youth leadership and mentorship of child-focused support groups have not gained real traction. Retreats, workshops, camps, regular self-help meetings, mentorship, helplines and other formats have been implemented, but have yet to generate evidence of their success in achieving treatment adherence, psychosocial health or successful transition to adult life. OVC programs lack an indicator to capture the number of OVC successfully transitioned to adult care.

## LACK OF EVIDENCE ON EFFECTIVE APPROACHES TO SUPPORT CAREGIVERS OF CHILDREN LIVING WITH HIV

Little is known of the effect of specific OVC interventions aimed at building the capacity of caregivers of children and adolescents living with HIV. Much of the work that is being done to encourage positive parental engagement of families living with HIV is anecdotal, and rigorous evidence would help to build a stronger case for relevant interventions.

## STIGMA IS STILL A MAJOR BARRIER

Stigma remains a threat to information-sharing and care-seeking. In many cases, caregivers fear that if their child tests positive, the child will suffer stigma and not be able to cope. In other cases, the mother is afraid to discover her own HIV status, or fears that she will be forced to share her own status with her partner if the child tests positive, and risks beating, abandonment, separation from other children and shaming in front of family and friends. For children living with nonbiological caregivers, denial of possible infection and fear that the child will suffer discrimination, continue to delay uptake of this vital service.

## UNDERSERVED AND HARD-TO-REACH HOUSEHOLDS: IS THERE A ROLE FOR SPECIALLY TRAINED COMMUNITY VOLUNTEERS IN THE PROVISION OF HOME TESTING?

While home testing was only reported in Kenya and provided by qualified counselors, it would be good to explore the potential role of trained community volunteers in provision of home testing. In hard-to-reach communities where the distance, time and expense of travel to a facility can be a barrier, where permission to test is best achieved at home and/or outside of clinic hours, or where a visit to a facility generates curiosity and gossip in the community, discrete home-based testing for targeted families might be part of the solution. Similarly, in households with many children, in mobile communities or where the consenting adult works during clinic hours, a home testing option might capture referrals that would be otherwise lost.

## Considerations for OVC programming

### REDUCE STIGMA AND BUILD COMPASSION FOR CHILDREN WITH HIV

It is vital to continue to build HIV-competent communities that protect children through awareness of threats that increase HIV vulnerability, increased male involvement in parenting and child health, and improved social support to HIV-positive children and their families. Efforts to reduce misinformation and reduce stigma and discrimination for PLHIV should include a particular focus on children living with HIV. Similarly, renewed efforts to produce strategic behavior change communication programming should include a particular focus on children living with HIV. Specific child-to-child approaches to build compassion and caring among children at community level, e.g., through the social engagement promoted by youth groups, and household-based strategies that reduce fear and promote compassion for children living with HIV, should also be considered.

### DEVELOP EVIDENCE-BASED APPROACHES TO ADDRESS HIV DISCLOSURE, POSITIVE LIVING AND TREATMENT ADHERENCE AMONG CHILDREN AND ADOLESCENTS

Age-appropriate support group guidelines, curricula and leadership training suitable for children living with HIV are essential for future OVC programming to ensure that program volunteers are able to offer ongoing services and support to children and adolescents identified through HTS activities. The development of child-to-child mentorship training and “camp-style” approaches could be effective in this setting. Building the evidence base of what works, including evaluation of positive parenting classes, positive living (including disclosure of a parent’s own status to children, role modeling and stigma management), support groups and savings groups — in relation to pediatric and adolescent testing rates, linkage to treatment and success on treatment — would help guide future investment and program development.

### CONSIDER THE NEEDS OF CHILDREN WHO MAY HAVE HORIZONTALLY ACQUIRED HIV

None of the sampled programs specifically addressed the needs of sexually active children and teens, early married

girls, victims of rape and other hard-to-reach children (children living outside of family care, children of sex workers). There were suggestions that “specialized programs” offer these services, but deliberate efforts to collaborate with them were not evident. It is important that OVC programs ensure access to child-friendly HIV information and HTS services for early married girls, victims of rape and all children who are willingly or unwillingly engaged in sexual activity. Some countries, including Zimbabwe, have excellent national guidelines, protocols and some emerging community models to respond to sexual violence and associated HIV risk, however these were not addressed within the OVC program.

### IMPROVE DATA MANAGEMENT TO ENABLE EFFECTIVE CASE MANAGEMENT

The example of Kenya’s OLMIS should serve to strengthen data collection and management systems in other countries and programs. Better age- and sex-disaggregated information alongside “category of service” would be instructive to inform program design, and would also be useful to understand the program’s influence on PMTCT adherence, reduced loss-to-follow-up or improved early infant diagnosis rates.

## Conclusion

Each of the four programs documented here has developed effective, replicable approaches to tackle the barriers that prevent children from successful engagement in HTS. These programs operate in complex, resource-constrained environments — familiar to all OVC programs worldwide — yet their creativity and persistence provide an inspiring glimpse of *what can be*.

However, we are still left with several important questions that require investigation to ensure the way forward is built on solid footing. We need a better understanding of children’s experiences with stigma, and clear guidance about the optimal timing and process of disclosure. Perhaps most urgently, we must address how to identify and care for children and adolescents who may have horizontally acquired HIV through mainstream (as well as specialized) OVC programs.

These case studies present an opportunity to learn from the experience of other programs, which in turn can inform continuous improvement in the types of interventions used to increase HTS within the OVC population. It is hoped that the information highlighted inspires new evidence and increasing innovation in the way that OVC programming can effectively meet the unique needs of children living with HIV, and contribute to the global effort of reaching 90-90-90.

## Annex: Literature Review on Barriers to HIV Testing and Effective Linkage to Care for Children

### BACKGROUND

Between April and September 2016, the Coordinating Comprehensive Care for Children (4Children) project visited and documented programs for children affected by HIV (OVC) in three countries. These include COGRI's Lea Toto program and FHI 360's APHIAplus program in Kenya, the World Education Inc./Bantwana Expanded IMPACT Program in Zimbabwe, and Pact's Yekoeb Berhan program in Ethiopia. The documentation involved review of project-level, country-specific and global reference documents, and key informant interviews and focus group discussions with USAID and program staff, community workers, health sector staff, caregivers and children. Through this process and through a review of relevant literature, 4Children has identified the following eight barriers.

### BARRIERS

#### BARRIER 1

Over-reliance on clinical providers undervalues the roles of local knowledge, peer-based interaction, family-based approaches and consistent follow-up — offered by trained community cadres (CCs) — that support early identification of HIV infection. Facility-based provider-initiated testing and counseling depends heavily on the presentation of illness to prompt HIV testing.<sup>23,24</sup> While active referral of HIV-infected parents engaged in care can improve testing uptake and yield, and identifies children prior to serious illness, the vast majority of parents still decline testing for their children.<sup>25</sup> Community volunteers are key to the mobilization of earlier uptake of HTS through screening, promotion of testing and accompaniment, thus avoiding delays that generate poorer outcomes, *especially for children*.<sup>26,27,28</sup> Achievement of the UNAIDS 90-90-90 targets is possible only if *all* at-risk individuals are mobilized to present for testing prior to the onset of illness.

Similarly, policies that exclude the community-based workforce from health-related “confidential” information impede the delivery of holistic care for children and their families. Community volunteers in some countries are forced to rely on personal relationships, rather than systems and processes, to gain access to information deemed “confidential”. Relegating community volunteers to a secondary role diminishes their credibility, and reduces the opportunity to establish a “one team” approach. Operationalizing case management depends on informed, HIV-literate community volunteers to provide support at household level. Directives and policies that condone their exclusion from the care team may actually contribute to the stigma and isolation barriers that they were intended to prevent.

#### BARRIER 2

Structural barriers between the health and social welfare sectors hinder a “whole child” approach. To achieve networks of care that are effective in supporting children, mutually reinforcing relationships between facility (health sector) and community-based (social welfare sector) services should be

mapped, mandated and resourced, and the contribution of OVC programs should be acknowledged.

Similarly, implementing partners face — and perpetuate — similar barriers between programs, by failing to create a shared vision and a more streamlined, uniform approach to implementation. While program managers may use multiple funding streams to enable a comprehensive intervention, program staff often treat each project as a freestanding entity, and therefore do not create mechanisms to share approaches and resources across interventions. Independent monitoring, data collection and reporting processes are obstacles to cross-fertilization and the candid sharing of information. Interagency competition, workload and accountability to ambitious work plans, geographical boundaries and the quest for attribution tend to obstruct our view of the “whole,” whether it's a whole community, a whole family or a whole child.

#### BARRIER 3

Stigma and fear of discrimination, along with misinformation, continue to be significant barriers to both testing and linkage to treatment, especially *where children are concerned*.<sup>29,30,31,32</sup> With resources flooding to the expansion of treatment, funding for public messaging, advocacy and leadership development to reduce HIV stigma has waned. Unfortunately, there is a particular brand of shame around HIV infection in children that perpetuates misconceptions and fears, and causes delays in HTS uptake and effective linkage to services, including:

- a. fear and shame regarding having to disclose a child's status to the child, and subsequently being compelled to discuss painful or taboo subjects;<sup>33,34</sup>
- b. for a mother, fear of discovering her own HIV status or being forced to share her status with her partner (as a result of child testing) can be profound, carrying the risk of beating, abandonment, separation from other children and shaming in front of family and friends;<sup>35</sup>
- c. for sexually active children, fear that their families and friends would reject them if their results were positive, in particular because of the assumption of “immoral” behavior;
- d. deep-seated worry that the child would face stigma and discrimination.

Although the epidemic is well into its fourth decade, both stigma and misinformation about casual transmission of HIV (e.g., through playground contact, through accidental encounters with sharp objects or through playing with used condoms found on the street) continue to cause painful exclusion and persecution of children known or suspected to have HIV. This is often done without explicitly identifying HIV, but characterizing the child as “naughty,” “willful” or “a troublemaker.” Even the intention to *protect* an HIV-positive child from stigma can have dangerous consequences. With low levels of HIV literacy and ambiguous guidance, well-

intentioned school authorities (especially at boarding schools) have inappropriately altered medication routines, delayed drug refills and even thrown out medications, ostensibly to avoid “outing” the HIV-positive child.

#### **BARRIER 4**

Identification of infection in older children and adolescents has not been sufficiently prioritized. It is now understood that about a third of HIV-infected infants have slow-progressing disease, thus substantial numbers of children in sub-Saharan Africa with perinatally acquired HIV have been presenting to health care services for the first time during adolescence.<sup>36</sup> However, while this age group is targeted for prevention activities, there is a widespread lack of awareness — a blind spot — around the possibility of HIV infections in asymptomatic older children, who may have either slow-progressing, vertically acquired infection or sexually transmitted HIV.<sup>37</sup>

In addition, dedicated health care services for sexually active children and teens are the exception rather than the rule, and little or no provision has been made for the special needs of this age group. The needs of early married girls, schoolgirls with “sugar daddies” and survivors of sexual and gender-based violence are not consistently or specifically addressed in community-based OVC programs. Screening algorithms that apply to at-risk adolescents are not widely used by clinical or community providers.<sup>38</sup>

Finally, policies in many countries have been slow to align age of consent with the actual behavior of adolescents, and have therefore failed to provide privacy to adolescents regarding HIV testing, disclosure, care and treatment.<sup>39</sup> Policies and protocols governing consent are often poorly understood by both HTS providers and community volunteers.<sup>40</sup> For children without a designated guardian, or those unable to obtain consent from unwilling or absent parents, there is rarely a “Plan B” that provides for a proxy guardian.

#### **BARRIER 5**

Lack of clarity about optimal timing and process are barriers to disclosure of HIV status to children resulting in low rates of disclosure in resource-limited settings.<sup>41,42,43,44,45,46</sup> Parents, caregivers and service providers at all levels are generally reluctant to inform a child of her/his HIV status, and often delay initiating discussions. Failure to disclose arises from:

- a. confusion about who should tell the child, and when;
- b. fear of inadvertent or inappropriate disclosure of child’s status or that of other family members;
- c. lack of disclosure training for service providers at all levels;
- d. desire to protect the child from psychological distress; underestimating the child’s own resilience and capacity;
- e. underestimating what children already know or suspect; underestimating the distress caused by excluding children from information and decision-making;
- f. fear that the child would hate or lose respect for her/his mother, disown her and/or run away from home.

There is increasing evidence that disclosure plays an important role in improving medication adherence and HIV-related outcomes.<sup>47,48</sup> While several studies show that children reported feeling sadness, grief and worry upon learning about their HIV infection, these negative feelings were often followed by a sense of relief and purpose.<sup>49</sup> Significantly, however, 4Children interviews with children, community volunteers and HTS providers revealed that *delays* in initiating this important conversation caused confusion, mistrust and anger among children. Adolescents interviewed described caregivers sidestepping their direct questions, providing incorrect information (intentionally or unintentionally), or otherwise handling disclosure poorly, and revealed that they responded by becoming rebellious, secretive, depressed and suicidal—which often resulted in nonadherence to treatment.

#### **BARRIER 6**

The shortage or rationing of HIV test kits and services is a critical constraint for OVC and prevention of mother-to-child transmission (PMTCT) programs in many countries.<sup>50,51</sup> OVC programs are mandated to screen, prioritize and mobilize thousands of HIV-exposed children for HIV testing. However, if demand creation outstrips the supply of HTS staff and HIV test kits, these children and their families are effectively denied the service. Joint planning processes at the highest levels are required to ensure informed decision-making and budgeting.

Similarly, reliance on unwieldy early infant diagnosis (EID) technology and centralized lab services result in slow turnaround on EID results that can be life-threatening.<sup>52,53</sup>

#### **BARRIER 7**

Failure to include men and fathers in maternal, newborn and child health, PMTCT, child care and parenting creates care-seeking obstacles for every family member.<sup>54,55,56,57</sup> There is the general recognition that the burden of care is largely placed on women, with low engagement of male caregivers. Family and cultural norms, such as household power dynamics and gender-based violence, often deter female caregivers from acting on the child’s behalf. In addition, low engagement of male heads of household can result in subtle or overt refusal to support a child known or suspected to be HIV-positive.

#### **BARRIER 8**

Distance to testing and treatment services for children continue to be a barrier.<sup>58,59,60</sup> Decentralized models for health care delivery have been developed to increase access to care in many rural settings, with demonstrated success. However, caregivers still report problems accessing clinics, most often due to lack of money, transportation and because roads were in poor condition, especially during the rainy season. In addition, lack of trained staff and erratic availability of pediatric formulations in rural clinics can delay linkage to treatment because of long distances to referral hospitals.

## **LEARNING QUESTIONS**

### **LEARNING QUESTION 1**

**What is the optimal age and process for disclosure to children? How can parents/caregivers, OVC volunteers**

**and clinical service providers work together to ease the process of progressive disclosure?** There is an urgent need for evidence-based guidance around the indicators of child readiness and for age-appropriate techniques and language.<sup>61,62,63</sup> There is no clear understanding about the different roles of the parent/caregiver, the community volunteer and the clinical service provider in this process. “Doing it right” is crucial not only to the psychosocial health of children, their treatment adherence and the maintenance of family integrity, but also to preventing onward transmission as expanding numbers of HIV-infected children attain adolescence and become sexually active. Volunteers and clinical staff need to feel confident about initiating and guiding age-appropriate conversations, as well as providing information that is both sensitive and technical. The evidence base for the development of guidance, curricula and tools is thin at best.

### LEARNING QUESTION 2

**What are the most effective, age-appropriate formats and methodologies for providing support to HIV-positive children and adolescents?** Evidence is needed to underpin the development of clear guidance, tools, training materials and a secure resource stream. Retreats, workshops, camps, regular self-help meetings, mentorship, helplines and other formats have been implemented, but have yet to generate evidence of their success in achieving treatment adherence, psychosocial health or successful transition to adult life. While youth activists for HIV prevention have been very influential in the past two decades, youth leadership and mentorship of child-focused support groups have not gained real traction.

### LEARNING QUESTION 3

**Is there a role for specially trained community volunteers in the provision of home testing?** In hard-to-reach communities where the distance, time and expense of travel to a facility can be a barrier, where permission to test is best achieved at home and/or outside of clinic hours, or where a visit to a facility generates curiosity and gossip in the community, *discrete home-based testing for targeted families might be part of the solution.* Similarly, in households with many children, in mobile communities or where the consenting adult works during clinic hours, a home testing option might capture referrals that would be otherwise lost. Expanding community entry points for infant and child HIV diagnosis through home-based HIV testing has been shown to improve paediatric case finding.<sup>64,65,66</sup> The customary, low-key presence of OVC volunteers in at-risk households provides a critical and often unique entry point.

### LEARNING QUESTION 4 What are the most effective formats and methodologies for providing support to parents and caregivers of HIV-positive children and adolescents?

Little is known of the effect of specific OVC interventions aimed at building caregiver capacity. Evaluation of positive parenting classes, positive living (including disclosure of a parent’s own status to children, role modeling and stigma management), support groups and savings groups in relation to paediatric and adolescent testing rates, linkage to treatment and success on treatment — would help guide future investment and program development.

## ENDNOTES

- 1 Joint United Nations Programme on HIV/AIDS (UNAIDS). 2015 Progress report on the Global Plan towards the elimination of new HIV infections among children and keeping their mothers alive.
- 2 PEPFAR. (2012). Guidance for Orphans and Vulnerable Children Programming. Available at: <https://www.pepfar.gov/documents/organization/195702.pdf>
- 3 CDC, PEPFAR, USAID (n.d.) Strategies for Identifying and Linking Infants, Children and Adolescents to HIV Care and Treatment
- 4 Ferrand RA et al. Causes of acute hospitalization in adolescence: burden and spectrum of HIV-related morbidity in a country with an early-onset and severe HIV epidemic: a prospective survey. *PLoS Med.* 2010; 7(2): e1000178.
- 5 Ferrand RA, et al. The effectiveness of routine opt-out HIV testing for children in Harare, Zimbabwe. *J Acquir Immune Defic Syndr* 2016;71(1): e24-29.
- 6 Anjuli D et al. Active referral of children of HIV-positive adults reveals high prevalence of undiagnosed HIV. *JAIDS Journal of Acquired Immune Deficiency Syndromes* (in print): 10.1097/QAI.0000000000001184
- 7 Ferrand R et al. Survey of children accessing HIV services in a high prevalence setting: time for adolescents to count? *Bull World Health Organ.* 2010; 88(6): 428-34.
- 8 Ferrand RA et al. A primary care level algorithm for identifying HIV-infected adolescents in populations at high risk through mother-to-child transmission. *Trop Med Int Health.* 2011; 16:349–55.
- 9 John-Stewart GC et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. *AIDS Care.* 2013; 25(9): 1067-76.
- 10 Vaz LM et al. Patterns of disclosure of HIV status to infected children in a Sub-Saharan African setting. *J Dev Behav Pediatr.* 2011.
- 11 Brown BJ et al. Disclosure of HIV status to infected children in a Nigerian HIV care programme. *AIDS Care.* 2011; 23(9): 1053-8.
- 12 Vreeman RC et al. Disclosure of HIV status to children in resource-limited settings: a systematic review. *Journal of the International AIDS Society* 2013; 16:18466.
- 13 Lowenthal ED et al. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. *Lancet Infect Dis* 2014; 14: 627-639.
- 14 Moodley K, Myer L, Michaels D, Cotton M. Paediatric HIV disclosure in South Africa— caregivers’ perspectives on discussing HIV with infected children. *S Afr Med J.* 2006; 96(3): 201–204.
- 15 Biadgilign S, Deribew A, Amberbir A, Deribe K. Barriers and facilitators to antiretroviral medication adherence among HIV-infected paediatric patients in Ethiopia: a qualitative study. *Sahara J.* 2009; 6(4): 148-54.
- 16 Ferris M et al. The influence of disclosure of HIV diagnosis on time to disease progression in a cohort of Romanian children and teens. *AIDS Care.* 2007; 19(9): 1088-94.
- 17 Vaz L et al. Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care STDS.* 2010; 24(4): 247-56.
- 18 Kranzer K et al. *Ibid.*
- 19 Ahmed S et al. Lost opportunities to identify and treat HIV-positive patients: results from a baseline assessment of provider-initiated HIV testing and counselling (PITC) in Malawi. *Tropical Medicine and International Health* 2016; 21(4): 479–485.
- 20 Duff P et al. Barriers to accessing highly active antiretroviral therapy by HIV-positive women attending an antenatal clinic in a regional hospital in western Uganda. *J Int AIDS Soc.* 2010; 13:37.
- 21 Wachira J et al. *Ibid.*
- 22 van Dijk JH et al. Barriers to the care of HIV-infected children in rural Zambia: a cross-sectional analysis. *BMC Infect Dis.* 2009; 9:169.

- 23 Ferrand RA et al. Causes of acute hospitalization in adolescence: burden and spectrum of HIV-related morbidity in a country with an early-onset and severe HIV epidemic: a prospective survey. *PLoS Med.* 2010; 7(2): e1000178.
- 24 Ferrand RA, et al. The effectiveness of routine opt-out HIV testing for children in Harare, Zimbabwe. *J Acquir Immune Defic Syndr* 2016 ; 71: e24-29.
- 25 Anjuli D et al. Active referral of children of HIV-positive adults reveals high prevalence of undiagnosed HIV. *JAIDS Journal of Acquired Immune Deficiency Syndromes* (in print): 10.1097/QAI.0000000000001184
- 26 Ahmed S et al. Improved identification and enrolment into care of HIV-exposed and -infected infants and children following a community health worker intervention in Lilongwe, Malawi. *Journal of the International AIDS Society* 2015; 18: 19305.
- 27 Kim MH et al. The Tingathe programme: a pilot intervention using community health workers to create a continuum of care in the prevention of mother to child transmission of HIV (PMTCT) cascade of services in Malawi. *J Int AIDS Soc*, 2012; 15(suppl 2): 17389.
- 28 Govindasamy D et al. Uptake and yield of HIV testing and counselling among children and adolescents in sub-Saharan Africa: a systematic review. *Journal of the International AIDS Society* 2015; 18: 20182.
- 29 Armstrong A et al. The voices, values and preference of adolescents on HIV testing and counselling. WHO, 2013. WHO/HIV/2013.135.
- 30 Braitstein P et al. 'Wamepotea' (they have become lost): outcomes of HIV-positive and HIV-exposed children lost to follow-up from a large HIV treatment program in western Kenya. *J Acquir Immune Defic Syndr.* 2011; 57: e40–e46.
- 31 Donahue MC et al. A "They have already thrown away their chicken": barriers affecting participation by HIV-infected women in care and treatment programs for their infants in Blantyre, Malawi. *AIDS Care* 2012; 24: 1233–39.
- 32 Buzdugan R et al. Positive attitudes to pediatric HIV testing: findings from a nationally representative survey from Zimbabwe. *PLoS One* 2012; 7: e53213.
- 33 Mburu G et al. Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. *Journal of the International AIDS Society* 2014; 17: 18866
- 34 Vreeman RC et al. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care STDS.* 2010; 24(10): 639-64.
- 35 Were E et al. A prospective study of frequency and correlates of intimate partner violence among African heterosexual HIV serodiscordant couples. *AIDS.* 2011; 25(16):2009-18.
- 36 Ferrand R et al. Survey of children accessing HIV services in a high prevalence setting: time for adolescents to count? *Bull World Health Organ.* 2010; 88(6): 428-34.
- 37 Kranzer K et al. Barriers to provider-initiated testing and counselling for children in a high HIV prevalence setting: a mixed methods study. *PLoS Med.* 2014; 11(5): e1001649.
- 38 Ferrand RA et al. A primary care level algorithm for identifying HIV-infected adolescents in populations at high risk through mother-to-child transmission. *Trop Med Int Health.* 2011; 16: 349-55.
- 39 Binagwaho A et al. Adolescents and the right to health: eliminating age-related barriers to HIV/AIDS services in Rwanda. *AIDS Care* 2012; 24: 936-942.
- 40 Kranzer K et al. *Ibid.*
- 41 John-Stewart GC et al. Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya. *AIDS Care.* 2013; 25(9): 1067-76.
- 42 Vaz LM et al. Patterns of disclosure of HIV status to infected children in a Sub-Saharan African setting. *J Dev Behav Pediatr.* 2011.
- 43 Brown BJ et al. Disclosure of HIV status to infected children in a Nigerian HIV care programme. *AIDS Care.* 2011; 23(9): 1053-8.
- 44 Vreeman RC et al. Disclosure of HIV status to children in resource-limited settings: a systematic review. *Journal of the International AIDS Society* 2013; 16: 18466.
- 45 Lowenthal ED et al. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. *Lancet Infect Dis* 2014; 14: 627-639.
- 46 Moodley K, Myer L, Michaels D, Cotton M. Paediatric HIV disclosure in South Africa—caregivers' perspectives on discussing HIV with infected children. *S Afr Med J.* 2006; 96(3): 201-204.
- 47 Biadgilign S, Deribew A, Amberbir A, Deribe K. Barriers and facilitators to antiretroviral medication adherence among HIV-infected paediatric patients in Ethiopia: a qualitative study. *Sahara J.* 2009; 6(4): 148-54.
- 48 Ferris M et al. The influence of disclosure of HIV diagnosis on time to disease progression in a cohort of Romanian children and teens. *AIDS Care.* 2007; 19(9): 1088-94.
- 49 Vaz L et al. Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care STDS.* 2010; 24(4): 247-56.
- 50 Kranzer K et al. *Ibid.*
- 51 Ahmed S et al. Lost opportunities to identify and treat HIV-positive patients: results from a baseline assessment of provider-initiated HIV testing and counselling (PITC) in Malawi. *Tropical Medicine and International Health* 2016; 21(4): 479-485.
- 52 Dube Q et al. Implementing early infant diagnosis of HIV infection at the primary care level: experiences and challenges in Malawi. *Bulletin of the World Health Organization* 2012; 90: 699-704.
- 53 Centers for Disease Control and Prevention, PEPFAR, USAID. Strategies for identifying and linking HIV-infected infants, children and adolescents to HIV care and treatment. (not dated)
- 54 Montgomery E, Van der Straten A, Torjesen K. "Male involvement" in women and children's HIV prevention: challenges in definition and interpretation. *J Acquir Immune Defic Syndr.* 2011; 57(5): e114-6.
- 55 Kanesathasan A et al. *Ibid.*
- 56 Wachira J et al. Factors underlying taking a child to HIV care: implications for reducing loss to follow-up among HIV-infected and -exposed children. *SAHARA J.* 2012; 9:20-29.
- 57 Merton S et al. Non-Uptake of HIV Testing in Children at Risk in Two Urban and Rural Settings in Zambia: A Mixed-Methods Study. *PLoS One.* 2016; 11(6): e0155510.
- 58 Duff P et al. Barriers to accessing highly active antiretroviral therapy by HIV-positive women attending an antenatal clinic in a regional hospital in western Uganda. *J Int AIDS Soc.* 2010; 13:37.
- 59 Wachira J et al. *Ibid.*
- 60 van Dijk JH et al. Barriers to the care of HIV-infected children in rural Zambia: a cross-sectional analysis. *BMC Infect Dis.* 2009; 9: 169.
- 61 Vreeman RC et al. *Ibid.*
- 62 Mburu G et al. *Ibid.*
- 63 Kanesathasan, A et al. *Ibid.*
- 64 Lugada E et al. Comparison of home and clinic-based HIV testing among household members of persons taking antiretroviral therapy in Uganda: results from a randomized trial. *J Acquir Immune Defic Syndr.* 2010; 55(2): 245-52.
- 65 Manyoni K et al. Community-based HIV testing of orphans and vulnerable children (OVC) to enhance linkage to services: 19th International AIDS Conference: Abstract no. THPE118.
- 66 Ahmed S et al. *Ibid.*

*Coordinating Comprehensive Care for Children (4Children) is a five-year (2014-2019), USAID-funded project to improve health and well-being outcomes for Orphans and Vulnerable Children (OVC) affected by HIV and AIDS and other adversities. The project aims to assist OVC by building technical and organizational capacity, strengthening essential components of the social service system, and improving linkages with health and other sectors. The project is implemented through a consortium led by Catholic Relief Services (CRS) with partners IntraHealth International, Pact, Plan International USA, Maestral International and Westat.*

