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Case Study on Improving HIV Testing and Services for Children Orphaned
or made Vulnerable by HIV (OVC)

APPROACHES OF THE YEKOKEB BERHAN PROGRAM FOR HIGHLY VULNERABLE CHILDREN IN ETHIOPIA

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Acronyms

CC	Community committee	MoWCA	Ministry of Women and Children Affairs
CCC	Community care coalition	OVC	Orphans and vulnerable children
CSI	Child Support Index	PEPFAR	U.S. President's Emergency Plan for AIDS Relief
GDP	Gross domestic product	PITC	Provider-initiated testing and counseling
HEW	Health extension worker	PMTCT	Prevention of mother-to-child transmission
HTS	HIV testing and services	PSNP	Productive Safety Net Program
HVC	Highly vulnerable children	USAID	United States Agency for International Development
MARPS	Most at-risk populations		
MoH	Ministry of Health		
MoLSA	Ministry of Labor and Social Affairs		

Introduction

PURPOSE

In spite of the dramatic success of HIV treatment programs around the world, children remain under-tested, 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 21 priority countries¹ received a virologic test to determine their HIV status within the first two months of life, as recommended by the World Health Organization (WHO). The same report reveals that only 31% of children living with HIV were receiving the antiretroviral treatment they needed.²

Childhood HIV infection is especially complex in terms of case finding, diagnosis and treatment requiring specific approaches depending 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

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.

multitude of practical barriers in achieving viral suppression, but they are perhaps even *more* constrained, subject not only to the wide range of household-level, developmental and societal barriers, but 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 throughout a child's development, using age-appropriate approaches. These 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 social support to children living with HIV and their families.

Acknowledging that OVC are at increased risk for HIV infection,³ and in alignment with PEPFAR technical guidance, OVC programs aspire to ensure that all individually registered OVC beneficiaries have a known HIV status. Over the past four years, many programs worldwide 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 HIV testing and services (HTS) for children.

METHODOLOGY

Between April and September 2016, 4Children documented work by OVC programs in three countries; these included Pact's Yekokeb Berhan program in Ethiopia, the World Education Inc./Bantwana Expanded IMPACT Program in Zimbabwe and COGRI's Lea Toto program and FHI360- led APHIAplus program in Kenya. At all sites the documentation included a comprehensive desk review (project, country-specific and global reference documents), meetings with the USAID OVC technical officer, site visits and key informant interviews or focus group discussions with program staff, various community workers, health sector staff, caregivers and children. Program staff reviewed the draft case studies and provided further input and clarifications.

The Setting

COUNTRY BACKGROUND

Ethiopia, formerly known as Abyssinia, is the oldest independent country in Africa.⁴ It is situated on the Horn of Africa, and is bordered by Djibouti, Eritrea, Kenya, Somalia, South Sudan, Sudan and Somaliland. With an area encompassing over 1.1 million square kilometers,⁵ it is about twice the size of France or the U.S. state of Texas. A population projected to stand at more than 100 million inhabitants⁶ comprised of more than 80 ethnic groups and as many languages⁷ makes Ethiopia the second most populous nation in Africa.⁸

In the past 15 years, Ethiopia has undergone significant economic and social change and has recorded some of the highest growth rates in the world—achieving 10% annual GDP growth in some years.⁹ However, although Ethiopia is one of the ten countries globally that has attained the largest absolute gains in its Human Development Index over the last several years, it still ranks 173rd out of 186 countries.¹⁰

At the heart of the country's strong economic and social performance has been the government's proactive role in shaping socioeconomic policy.¹¹ With its goal of making

1 Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, the Democratic Republic of the Congo, Ethiopia, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Uganda, the United Republic of Tanzania, Swaziland, Zambia and Zimbabwe.

2 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.

3 PEPFAR (2012). Guidance for Orphans and Vulnerable Children Programming. Available at: <https://www.pepfar.gov/documents/organization/195702.pdf>

4 <http://www.nationsonline.org/oneworld/ethiopia.htm>

5 Library of Congress — Federal Research Division. Country Profile: Ethiopia; available online at: <https://www.loc.gov/rr/frd/cs/profiles/Ethiopia.pdf>

6 The World Bank: Ethiopia data; available online at: <http://data.worldbank.org/country/ethiopia>

7 Hudson, Grover (2012). *Ethnic Group and Mother Tongue in the Ethiopian Censuses of 1994 and 2007*. *Aethiopia* 15: 204-218

8 United Nations Economic Commission for Africa (2016). *The Demographic Profile of African Countries*; available online at: https://www.uneca.org/sites/default/files/PublicationFiles/demographic_profile_rev_april_25.pdf

9 UNDP (2015). *National Human Development Report 2014 Ethiopia. Accelerating Inclusive Growth for Sustainable Human Development in Ethiopia*.

10 *Ibid*

11 *Ibid*



Health Extension Workers are vital to providing rural communities with preventive and promotive health services.

Photo by Ric Francis for CRS

Ethiopia a middle-income country by 2025, the government has been investing heavily in economic and social infrastructure, streamlining public services, revamping the tax collection system, and supporting small and medium enterprises. It has also prioritized key sectors such as industry and agriculture as drivers of sustained economic growth and job creation. The most recent data¹² reveal that in 2015 the gross domestic product registered a growth rate of 9.6%, which was accompanied by an increase in the savings rate, and backed by a prudent fiscal policy, the budget deficit was contained at 2% of gross domestic product.

High economic growth and enhanced pro-poor investments have helped reduce poverty in both urban and rural areas.¹³ Since 2005, 2.5 million people have been lifted out of poverty, and the share of the population below the poverty line fell from nearly 39% to 26% in 2012-13 (using a poverty line of US\$0.60/day). However, because of high population growth, the absolute number of individuals experiencing poverty (about 25 million) has remained largely unchanged over the past 15 years. Also, despite the generally favorable policy and institutional framework, the effects of Ethiopia's rapid growth and development remain unevenly distributed throughout the country with "emerging" regions¹⁴ remaining relatively disadvantaged.

HEALTH AND SOCIAL WELFARE SERVICES CONTEXT

Ethiopia's major vehicle for social protection is the Productive Safety Net Program (PSNP), which has provided transfers to poor and food- insecure rural households since 2005. The program is well targeted, and has achieved many positive outcomes (reduction of the food gap, stabilizing assets, increasing access to basic social services and improving household-level diet diversity). Ethiopia still has higher than expected rates of malnutrition compared with countries at

the same income level, and utilization of health services even among PSNP households remains low.¹⁵

Ethiopia launched its National Social Protection Policy in 2014. The policy introduces the concept of a "sustainable social protection system." Various strategies and programs are underway to support the implementation of the policy, although often these are implemented in a fragmented manner.¹⁶

Despite efforts to expand pro-poor service delivery programs, the utilization of basic services by households experiencing poverty remains a concern. These households continue to face barriers in accessing basic social services. Registration of children at birth remains very low, with more than 90% of children remaining unregistered (2016),¹⁷ these children often have a lower level of school attendance than their peers (almost 1.8 times lower for primary school attendance in 2014).¹⁸ Overall trends in access to basic health services have, however, shown dramatic improvements over the last ten years, and the public sector remains the predominant player in the sector. Primary health care units have been expanded, with nearly 3,200 health centers and more than 16,000 health posts now providing free maternal, newborn and child health services. Life expectancy, a key component of the Human Development Index, has increased for both men and women.

Ethiopia still suffers from an acute shortage of health workers at every level, with rural areas — where 85% of the population live — remaining chronically underserved. To address this, the Health Extension Program currently employs more than 39,000 trained health extension workers (HEWs) — all women — to deliver free preventive and promotive services at community level.¹⁹ This program was initially established in rural areas in 2003, and in 2010 expanded to urban areas. HEWs have a wide-ranging mandate. In rural areas, HEWs are tenth-grade graduates who receive one year of training before being deployed to health posts where they provide primary health care at household level. In urban areas, the Ministry of Health (MoH) recruits nurses and provides them with a three-month health extension training before deploying them to work at community level.

Challenges also remain with quality of service delivery. Maternal health care has lagged well behind other health statistics, and utilization of basic services by the poor and less educated remains a concern.²⁰ Data from the 2016 Demographic and Health Survey shows that although almost all health posts provide free antenatal care services, only 53% of women with no education obtained antenatal care services from a skilled provider, compared to 98% of women with more than a secondary education.²¹ The same report shows that only 39% of children aged 12-23 months have received all basic vaccinations; a shocking 16% of children

12 <http://www.tradingeconomics.com/ethiopia/gdp-growth-annual>

13 UNDP (2015). *National Human Development Report 2014 Ethiopia* and <http://hdr.undp.org/en/countries/profiles/ETH>

14 Afar, Somali, Gambella and Benishangul-Gumuz regions

15 UNICEF (2016). *Ethiopia. Social Protection: Access of the poor and vulnerable to basic social services. Good practices: Linking safety net clients with complementary social services.*

16 *Ibid*

17 UNICEF (2016). *Ethiopia: Vital events registration launched*; available online at: <https://unicefethiopia.org/tag/birth-registration/>

18 UNICEF (2016) *Ethiopia. Social Protection: Access of the poor and vulnerable to basic social services. Good practices: Linking safety net clients with complementary social services.*

19 *Ibid*

20 *Ibid*

21 Central Statistical Agency Addis Ababa, Ethiopia and ICF USA (October 2016). *Ethiopia Demographic and Health Survey 2016 Key Indicators Report*; available online at: <http://dhsprogram.com/pubs/pdf/PR81/PR81.pdf>

in this age group have received no immunizations at all. Nutrition findings are also very worrying, with 38% of children under five considered short for their age or stunted and 18% severely stunted.

ETHIOPIA'S HIV EPIDEMIC AND RESPONSE

Over the last two decades, strong measures have delivered impressive gains in reducing both incidence of HIV and related mortality. The 2016 projected national adult HIV prevalence was 1.1%,²² sharply down from 2.4% in 2009, and Ethiopia has reduced new infections among children by 60% since 2009.²³

Ethiopia's epidemic can now be characterized as urbanized, feminized and fueled primarily by key populations.²⁴ The Federal HIV/AIDS Prevention and Control Office Strategic Plan 2015-2020 is currently guiding the national response, and describes the strategies through which the country will achieve its 90-90-90 targets by 2020.

The introduction of lay counselors and provider-initiated testing and counseling (PITC) at all public health facilities has greatly expanded access to HIV testing, and uptake has been strong. HIV testing and services (HTS) are now available countrywide at public health center and hospital levels, and health center staff work with HEWs to provide outreach HTS at health post level. As part of their role, HEWs are responsible for HIV prevention and control, including the identification, referral and follow-up of clients who need HIV testing and treatment services. According to the [2016 DHS](#),²⁵ only 40% of women and 43% of men had ever been tested and had received the results of their last test. It is promising that the 2013 most-at-risk populations (MARPs) survey²⁶ shows that 83% of female sex workers had ever been tested for HIV.

Prevention of mother-to-child transmission (PMTCT) services are integrated with maternal, newborn and child health services at health center and hospital levels. The Ethiopian Ministry of Health reports that in 2012-2013, 68.9% of pregnant women were tested for HIV, and of the HIV-positive pregnant women identified, only 42% of mothers and 18% of their infants received antiretroviral prophylaxis.²⁷

Antiretroviral therapy (ART) is available in 1,047 health facilities throughout the country, of which 849 of these facilities are health centers.²⁸

The Ethiopian Ministry of Health estimated in 2012 that nearly 110,000 children under age 15 were living with HIV.²⁹ While there is very little data available, the [UNAIDS 2015 Progress Report](#) estimates that in 2014, only 25% of HIV-exposed infants received early infant diagnosis, and only 22% of children ages newborn to 14 years living with HIV received antiretroviral therapy. Without treatment, illness progression can be rapid, and is often fatal in the first few months of life.

Ethiopia's Federal HIV and AIDS Prevention Office has acknowledged that the need to identify and implement



Country-wide access to HIV testing and counseling services has contributed to impressive reductions in HIV incidence and related HIV mortality in Ethiopia.

Photo by David Snyder for CBS

strategies to increase coverage is urgent. The agency's 2015-2020 Strategic Plan outlines priority interventions required to achieve the country's 90-90-90 targets, which include the rollout of Option B+ for enhanced PMTCT; improving availability of early infant diagnostic services and supplies; improving availability of ART monitoring, including viral load testing; enrolling all children living with HIV in treatment regardless of CD4 count at time of diagnosis; and improving adherence and retention in care by strengthening the role of families in care and treatment.

BARRIERS TO HIV TESTING FOR CHILDREN

For the past three years, all health facilities in Ethiopia have faced severe shortages of HIV test kits, leading to rationing of HTS. In many facilities, HIV testing is restricted to PITC for clients showing symptoms of HIV-related illness and for women enrolled in PMTCT. If HEWs are aware of someone who should be tested, they generally only refer that individual for testing when they know the kits are available. This leads to long delays and loss to follow-up in many cases.

Population-level messaging on HIV has diminished dramatically across the entire National AIDS Program, and is now limited to PMTCT and treatment adherence messaging. Community capacity enhancement activities around HIV have been discontinued completely in some constituencies, while in others, coffee ceremony discussions —once the cornerstone of community communication on HIV —no longer receive the support they require.

HIV among children is poorly understood, and children living with HIV are especially vulnerable to stigma and discrimination. Fear of HIV-related stigma and discrimination remains a formidable challenge, hindering access to accurate information and services. The mutually reinforcing triad of

22 Ethiopian Health and Nutrition Research Institute Federal Ministry of Health (August, 2012). *HIV Related Estimates and Projections for Ethiopia*.

23 UNAIDS (2015). *Global AIDS Progress Report on the Global Plan towards the elimination of new HIV infections among children and keeping their mothers alive*.

24 Ethiopia Public Health Institute, Centers for Disease Control and Prevention, USA, and Ethiopia Federal HIV and AIDS Prevention Office (2015). *Ethiopian National Key Population HIV Bio-behavioral Surveillance Round I, 2013 Report* [version 5, May 29, 2015, of report originally dated November 2014].

25 CSA Ethiopia and ICF USA (2016). *Ethiopia Demographic and Health Survey 2016. Key Indicators Report*.

26 Ethiopia Public Health Institute, Centers for Disease Control and Prevention, USA, and Ethiopia Federal HIV and AIDS Prevention Office (2015). *Ethiopian National Key Population HIV Bio-behavioral Surveillance Round I, 2013 Report* [version 5, May 29 2015].

27 Federal Democratic Republic of Ethiopia HAPCO (2014). *National HIV/AIDS Strategic Plan 2015-2020*.

28 *Ibid*

29 EHNRI FMOH (2012). *HIV Related Estimates and Projections for Ethiopia*.

Tsehay and Solomon's story*

Tsehay and her 12-year old son, Solomon, are both living with HIV. Solomon has been on ART since he was small. He used to ask his mother how long he had to continue taking syrup, but fearing what stigma would do to her son, Tsehay would avoid the question. The neighbors already knew that Tsehay was living with HIV, however, so Solomon was often rejected by other children. When watching TV together they would chase him away, and tell him he could not watch with them. He thought it was because of his mother's HIV status.

When Solomon was ten years old, he visited his mother at her workplace and noticed that she and a friend were eating together and sharing the same plate. Solomon told his mother's friend not to eat with her, because she was HIV positive. The friend replied that he knew, and that he was himself. Together, Solomon's mother and her friend decided that it was time to tell Solomon he was also living with HIV, and they did so. It was difficult. Solomon wanted to move to a different town where no one would know them or their status, and where they could start their lives over. Solomon has now joined a support group for children, is focusing on his education, and is doing better. Tsehay has joined a savings and loans group, and with last year's savings she bought a television so that Solomon can now watch TV at home.

*Names have been changed to protect confidentiality.

denial, misinformation and stigma are significant constraints to both information sharing and care-seeking behavior, especially in rural areas. A 2012 study in a rural setting found that people strongly associated HIV infection with shame or bad behavior, and indicated that people living with HIV would be isolated or discriminated against.³⁰ The [People Living with HIV Stigma Index study](#) conducted in 2011 by Network of Networks of HIV Positives in Ethiopia (NEP+) found that a significant proportion of both men and women living with HIV tend to keep their HIV status secret from their children (60%), community leaders (66%), religious leaders (54%), work colleagues (63%) and friends/neighbors (44%), and that gossip is the most common manifestation of stigma at both family and community levels.³¹ It also reported that discrimination is manifested in the workplace in the form of revision of job description or the nature of work, refusal of promotion, denial of employment opportunities, and firing from job as a result of their HIV status.

There is a dearth of literature on this topic about the lived experience of children living with HIV in Ethiopia but extrapolating from research in other countries, it can be assumed that their caregivers' fears are not groundless: children with HIV are especially vulnerable to stigma and discrimination.^{32, 33}

Case Study

INTRODUCTION TO THE PROGRAM

This case study was conducted to document the work of the Yekokeb Berhan Program for Highly Vulnerable Children in Ethiopia, a large, comprehensive response to child vulnerability. Yekokeb Berhan was implemented through a cooperative agreement between Pact and USAID/Ethiopia. Between April 2011 and September 2016, Yekokeb Berhan

contributed to the strengthening of a child-focused social welfare framework in Ethiopia that aims to help all children, including highly vulnerable children (HVC),³⁴ to thrive. As a PEPFAR-funded initiative, the program prioritized communities most affected by HIV to ensure that children and families affected by HIV and AIDS, who often are the most vulnerable, are appropriately targeted and supported. Pact, the grant's prime recipient, works in partnership with the government of Ethiopia through the Ministry of Women and Children Affairs (MoWCA), consortium partners FHI 360 and Child Fund, and (in August 2016) 32 local NGO partners to implement project activities with an annual caseload of 325,000 beneficiaries.

Yekokeb Berhan was designed to improve the accessibility and quality of services, including HIV services, for HVC in Ethiopia by strengthening systems and structures of both government and civil society in a sustainable, comprehensive and coordinated manner. Its purpose was to improve coordinated delivery of seven core services: 1) economic strengthening, 2) educational support, 3) food and nutrition, 4) health care, 5) legal protection, 6) psychosocial support, and 7) shelter and care. The program also aimed to extend the rollout of the [Standard Service Delivery Guidelines for Orphans and Vulnerable Children's Care and Support Programs](#). It was designed to achieve the following results:

1. regional and local government and civil society have strengthened capacity to collaboratively provide, manage and monitor integrated, comprehensive care to HVC and their families;
2. HVC and their families have increased access to health and social services;

30 Federal HIV/AIDS Prevention and Control Office (2010). *Report on progress towards implementation of the UN Declaration of Commitment on HIV/AIDS*.

31 NEP+ (2011). *The People Living with HIV Stigma Index Report Ethiopia. Summary of Findings*.

32 Armstrong A. et al. *The voices, values and preference of adolescents on HIV testing and counselling*. WHO, 2013. WHO/HIV/2013.135.

33 Braitstein P. et al. (2011) '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*. 57: e40–e46.

34 In Ethiopia, the preferred nomenclature for child-focused programming is "highly vulnerable children" (HVC). The definition encompasses the commonly used Orphans and Vulnerable Children (OVC), and refers to children under age 18 whose safety, well-being and/or development are at significant risk due to inadequate care, protection or access to essential services. HVC includes those who are orphaned; receive inadequate adult support because of death, abandonment, economic distress, or chronic illness; have HIV/AIDS or are suspected of having HIV; are directly affected by armed conflict; live outside of family care; or in some other way have suffered from a collapse of traditional social safety nets in their communities." Ref: <http://hvc-tulane.org/about-us/highly-vulnerable-children/>

3. community members and households caring for vulnerable children have increased and ongoing capacity to meet their basic needs; and
4. shared learning and the evidence base to improve programming and inform policy and program investment are strengthened.

Yekokeb Berhan created an infrastructure that supported community volunteers to work closely with HEWs, extending their reach, reducing their workload, and streamlining the provision of quality essential services to the most vulnerable children and families. The program’s volunteers provided a vital interface between community-based service delivery platforms —such as community care coalitions (CCCs)³⁵ and community committees (CCs)³⁶ —and the HEWs.³⁷

Program results

Over the course of the program’s five years, nearly 900,000 children and caregivers have benefitted from Yekokeb Berhan services.³⁸ HVC and their caregivers were supported by a comprehensive network of structures and service providers, with community volunteers at the forefront. Yekokeb Berhan engaged and trained over 20,000 community volunteers (of whom more than 75% were women) to work with CCCs, CCs and HEWs to identify children and caregivers vulnerable to HIV, and link them to the HIV continuum of care. The most common services provided to families have been shelter and care, psychosocial support, health care and education.

Between October 1, 2015, and March 31, 2016, a total of 538,714 beneficiaries received services through the program, of which 321,318 were HVC (158,790 males and 162,528 females) and 217,396 were adult caregivers (53,660 males and 163,736 females). This represents 101.4% of the program’s annual target of 316,822. A total of 209,228³⁹ children have now transitioned or graduated from project support.

In that same reporting period, the program initiated referrals of 21,000 children in need of HIV counseling and testing. Of those referred, 55% (11,607) reached the facility, although only 72% of those who reached the site (8,340 HVC) actually received their HIV test and know their HIV status (Table 1).⁴⁰ Of the HVC who received HIV tests, 386 received positive test results, for a



Community volunteers are the arms and legs of Yekokeb Berhan’s outreach, with more than 20,000 volunteers trained to identify vulnerable children and caregivers and link them to HIV care.

Photo by Francesca Stuer

yield of 4.6% among those tested. Of the children with newly diagnosed HIV, 89% (344) were successfully linked to treatment services.

The results over this period are consistent with the trend established over the life of the project, during which data showed that 65-72% of HVC who reached a testing site received the service they needed, and that roughly 4% of those tested were seropositive.

Among adult caregivers, 58% of the 14,231 caregivers referred for testing and counseling (between Oct. 1, 2015 and March 31, 2016) accessed the service, but only 40% actually received an HIV test and are assumed to know their HIV status. It is significant that more children were successful than adults in receiving testing services, indicating that children were prioritized for testing once they reach the testing site, even where test kits are limited.

The lack of test kits is believed to be the primary reason for the failure of referred clients to receive the service. In fact, many referred clients were known to defer testing simply because upon arrival at the health facility, they found out that there were no test kits available, or because they had been informed by the HEW that test kits were not available. Thus,

Table 1

OUTCOME OF HVC TESTING REFERRALS: OCT. 1, 2015 – MARCH 31, 2016 ⁴⁰				
HVC referred for testing	HVC who reached testing site	Of HVC who reached the testing site, received HIV testing service	Of HVC tested, received positive result	Of HVC with positive test results, linked to treatment
21,127	11,607 (55%)	8,340 (72%)	386 (4.6%)	344 (4.1%)

35 A CCC is multisectoral platform comprised of community leaders and representatives, mandated by government to identify vulnerable people within their community (not only HVC), facilitate their access to the services they need, and ensure basic follow-up.

36 Where CCCs did not exist, the program established community committees (CCs) to serve as a platform for HVC service delivery.

37 For more information on the case management process utilized within Yekokeb Berhan, please see http://ovcsupport.org/wp-content/uploads/2017/06/4Children_YBEthiopia_17OS079_FINAL_rev1.pdf

38 Yekokeb Berhan Program for Highly Vulnerable Children (April 20, 2016). *Semi-annual progress report to PEPFAR FY16 (October 2015-March 2016)*.

39 Yekokeb Berhan Program for Highly Vulnerable Children (April 20, 2016). *Report on the Transitioning of Sites and Beneficiaries. Phase III (October 2015-March 2016)*.

40 We note that reporting of disaggregated child-specific data only started in FY2014, in response to new PEPFAR requirements.

Table 2

UNDIAGNOSED HIV AMONG HVC RELATED TO SHORTAGE OF HIV TEST KITS: OCT. 1, 2015 – MARCH 31, 2016			
HVC referred for testing	HVC who failed to reach testing site	Of HVC who reached testing site, failed to receive HIV testing service	Of HVC who failed to receive service, projected to be seropositive
21,127	9,520 (45%)	3,254 (28%)	150 (4.6%)

in a single six-month period, this resulted in at least 3,254 children failing to receive testing services and a projected total of 150 children with suspected HIV infection who remain undiagnosed and untreated (Table 2).

BRINGING CHILDREN TO HIV SERVICES

The Yekokeb Berhan approach focused squarely on children and caregivers affected by and living with HIV, and prioritized children living with HIV for enrollment and service delivery. Acknowledging that HVC are at increased risk of HIV,⁴¹ a core element of Yekokeb Berhan’s design was the deliberate process of linking children to HIV testing, care and support services (Annex 1). This could only be done by identifying and tackling the barriers to child testing, in particular:

- Caregivers’ concerns about the implications of positive results on the child’s mental health, relationships with others, school performance and life path;
- Misconceptions about childhood HIV and the need for/ effectiveness of treatment;
- Low perception of risk of HIV infection, especially for infants and young children;
- Chronic shortage of HIV test kits;
- Insufficient time in the HEW workload to support caregivers toward sound decision-making and facilitate their uptake.

Cognizant of the barriers to both access and uptake, the program devised three key strategies to guide this process:

1. Utilize comprehensive HVC care as a doorway to HIV testing and services. Targeting each community’s most vulnerable children for the purpose of providing a range of services allows the program to serve as a doorway, casting a wide net without stigmatizing any child or family. Individualized assessment of each registered child allows for the promotion of specific referrals, including HIV services.
2. Harness the power of the HVC workforce to increase demand for HIV testing and services. Widespread fear, mistrust and misinformation are barriers best overcome through relationships with trusted, respected, trained service providers who “speak the same language,” and are reliably available for information-sharing and problem-solving.

3. Strengthen the health system to reach vulnerable HVC households. Systems approaches were needed to address the barriers posed by the chronic shortage of HIV test kits and to extend the reach of the overloaded HEW cadre.

STRATEGY #1: UTILIZE COMPREHENSIVE HVC CARE AS A DOORWAY TO HIV TESTING AND SERVICES

The program designed a structure that supports the government’s efforts to use HEWs to reach into every vulnerable household with information, referrals and assistance. Community-level platforms⁴² (CCCs and CCs) were purposefully selected to facilitate program delivery for two reasons: 1) they are nested in the local communities, know their people well, and are thus expected to do a better job of beneficiary identification and follow-up than higher-level entities, and 2) through their multisectoral nature they are able to facilitate referral of program beneficiaries to services of various sectors. To help the CCCs and CCs understand their roles and engage effectively, Yekokeb Berhan introduced several training modules, including *The Coordination of Care, Use of the Child Support Index (CSI) Tool to Identify HVC, and Better Parenting*.

With the program’s support, CCCs and CCs recruited and managed community volunteers to provide support to HEWs, focusing on promoting and facilitating HIV testing for children and their caregivers, as well as pregnant women. Through its massive volunteer workforce, the program leveraged every possible opportunity to remove barriers and to promote HTS including:

- one-on-one counseling during home visits;
- community conversation sessions;
- testimonials by volunteers who have disclosed their HIV positive status; and
- savings and loans group meetings and life-skills support group meetings.

In addition, to stem the incidence of infection among infants and to reduce orphaning, the program also promoted (through the same communication channels) HIV testing for pregnant mothers, and facilitated their access to PMTCT services. For mothers whose test results were positive, volunteers worked closely with HEWs to provide multiple forms of relevant support, and to ensure adherence to treatment protocols.

41 PEPFAR (2012). *Guidance for Orphans and Vulnerable Children Programming*. Available at: <http://www.pepfar.gov/documents/organization/195702.pdf>

42 In Amhara and Tigray, the program aligned with government policy directing all government and NGO programs to work with CCCs to identify beneficiaries and follow-up on the services they receive. This ensures service to all vulnerable individuals, while avoiding duplication. In other regions where CCCs did not exist, the program established CCs to serve as a platform for HVC service delivery.



Community Care Coalition in Bale Goba, Oromia Regional State, is part of the Yekokeb Berhan program strategy for reaching every vulnerable household in a community.

Photo by Francesa Stuer

The program followed a three-step process (assessment, referral, follow-up) to bring children and their families to HIV testing and services:

Step One: Assessment

The process was initiated by the CCC or CC, whose members compiled the list of the vulnerable children in each community. A child was considered vulnerable based on the CCC/CC's familiarity with the households in their community (and knowledge of households experiencing poverty), or because they had received assistance from another USAID-funded OVC program, or by referral from another program or by the local kebele (the lowest administrative unit, similar to a neighborhood). The list was verified to ensure that each identified child was under 18 years of age and met one or more preset vulnerability criteria, which included:

- ✓ single or double orphanhood;
- ✓ HIV-positive status of child or caregiver;
- ✓ caregiver is chronically ill;
- ✓ child living outside family care;
- ✓ child in conflict with the law;
- ✓ child living with disability;
- ✓ child- or youth-headed household;
- ✓ displaced child;
- ✓ moderate to severe malnutrition;
- ✓ stigmatization or marginalization;
- ✓ signs of abuse, violence or exploitation.

The community volunteer then conducted home visits, and used the CSI evaluate the child's needs. The findings were shared with the CCC or CC, where the tool was scored and program eligibility determined. Volunteers worked with the community facilitator to develop a care plan for the child

and for the household. The child then received tailored services as expressed in their care plan; all other children in the household benefited from Yekokeb Berhan's household-level interventions. As the program focused on children who are at risk of HIV, the care plan always included counseling for the caregiver and child to encourage HIV testing and services. Coaching and mentoring focused on reducing stigma, allaying fears, and correcting misconceptions about children and HIV.

Step Two: Referral

When volunteers identified the need for a service (including HTS) and had prepared the client to accept it, the volunteer informed the CCC or CC. In the case of HIV testing, the CCC or CC would then make the formal referral in one of two ways:

- a. *Where the health facility accepted the Yekokeb Berhan referral form (Annex 2), the CCC or CC completed the referral form and gave it to the volunteer or community facilitator who then acted as messenger, delivering the form to the health facility and making an appointment for the referred client(s). This preferred referral mechanism allowed the volunteer to verbally inform the client(s) of the appointment, and if the client wished, the volunteer would accompany them. In this case the CCC played a direct role in mediating on behalf of the HEW, and, importantly, reduced her workload, or*
- b. *Where the health facility required the use of the Ministry of Health (MoH) referral form,⁴³ the CCC or CC used the Yekokeb Berhan referral form to communicate the names of referred clients to the HEW. The HEW then transferred the information to the MoH referral form, made the client's appointment, and worked with the volunteer to communicate with the client household.*

To reduce the risk of a client being turned away because of HIV test kit shortages, someone from the team (the community facilitators, volunteers, HEWs or a CCC/CC member) first checked with the health facility (by telephone or in person) to determine whether HIV test kits were available. When they were confident that the referral would be honored, they facilitated access to testing. If the caregiver wished, the community volunteer would accompany them for testing and counseling.⁴⁴

Step Three: Follow-up

When a caregiver and/or child were found to be seropositive, the facility-level HTS provider would inform the HEW who provided follow-up. As HEWs and the health facility staff were bound to confidentiality, community volunteers relied exclusively on their relationships with clients to learn the outcome of testing. In their work with households and communities, volunteers highlighted the importance of personal disclosure to enable vital follow-up support.

The client's disclosure is the key that allows the volunteer to provide home-based adherence support and ongoing

43 No sample provided as this is only available in Amharic.

44 In Ethiopia, HTS is mainly provided at health facility level. Although they might be used to reach most-at-risk populations or remote areas, mobile or outreach HTS is not available to the general population in urban areas where Yekokeb Berhan operates.

The HEW and the health facility staff, bound by professional confidentiality, cannot disclose any client's HIV status to a community volunteer or to the CCC/CC. Community volunteers rely exclusively on the strength of their relationships with clients to learn the outcome of HIV testing.

referrals until the HEW or community facilitator supporting the volunteer is confident that the client can maintain adherence. However, in most cases, the strict application of the Ministry's confidentiality policy and the client's reluctance to disclose their status for fear of stigma seriously constrain the ability of community volunteers to provide any adherence support.

Weekly or monthly, health facilities provided summarized, statistical feedback to the CCC/CC, relaying the total number of clients tested for HIV, how many had tested positive, and the number linked to treatment services. *Feedback on individual client status was not shared.*

STRATEGY #2: HARNESS THE POWER OF HVC WORKFORCE TO INCREASE DEMAND FOR HIV TESTING AND SERVICES

Case study respondents all mentioned fear of stigma and discrimination of their children as one of the most important deterrents to HIV testing. In order to increase HIV case detection among children in a high-population, low-prevalence setting, the program focused on geographic areas with highest prevalence (urban and semi-urban areas) and employed a non-stigmatizing, community-based approach to identify children for HIV testing. On the frontlines of the Yekokeb Berhan program were thousands of volunteers, drawn from their own communities to serve the most vulnerable families through linking them with a comprehensive package of services, including HIV services for those who needed it. Through forging trusting relationships with households, they were able to provide sensitive information, perform delicate assessments, and make timely and relevant referrals. Engaging a workforce that can enter households and establish a relationship of trust is crucial to overcoming barriers of fear and mistrust.



Local implementing partners from the project provide supportive supervision, including weekly meetings and case management discussions.

Photo by Francesca Stuer

An effective volunteer network must be carefully recruited and selected, trained and mentored, mandated and supervised, and appraised and rewarded for its service. Yekokeb Berhan supported CCCs and CCs to recruit over 20,000 volunteers who were trained to conduct weekly home visits, use the CSI tool, provide basic case management services, participate in follow-up care planning, facilitate access to services, and provide household-based training and support. An extensive array of training materials was developed, including several specifically to support HIV-related interaction.

Of the many excellent standardized guides, manuals and job aids developed across the program's seven core areas of support, those most relevant to HIV-related services included:

- Child Support Index and Care Plan Training
- Actions to Facilitate Continuum of Care for HIV Positive Children and Caregivers
- Supplementary Guidance on How to Better Serve HIV-affected Children and Their Families
- Guidance on Disclosure
- How to Conduct a Rapid Survey on HIV Counseling and Testing
- Child Protection Policy
- Child Protection Policy & Procedures Facilitator's Manual for Staff Orientation
- Supplementary Guidance on Stigma and Discrimination

As part of the program's effort to tackle fear and mistrust among its clients, Yekokeb Berhan volunteers made a commitment to serve for at least two years to provide continuity and stability in the relationships they build with children. As a new volunteer stepped in to replace a volunteer leaving the service, the program tried to ensure a period of overlap to allow the relationship with the child and family to transition. The program's "buddy system" also helped to ensure continuity in child and family care: all community volunteers were paired with a buddy to help each other in their work, sometimes share activities, and introduce a replacement volunteer to the child and family if necessary. Community volunteers were to be responsible for no more than 25 children each. The overall aim was to spend no more than 10-12 hours per week doing this voluntary work for which they received a monthly stipend of 200 Ethiopian birr (about USD\$10) to cover local transport costs.

A cadre of community facilitators provided direct support to volunteers. Community facilitators were employees of Yekokeb Berhan's local implementing partners who provided day-to-day support to 10-15 community volunteers.⁴⁵ Their duties included on-site supportive supervision and mentoring; facilitating weekly meetings with volunteers for experience sharing, case management discussion and refresher training; and problem-solving assistance as needed. In some cases, community facilitators also worked with

⁴⁵ Community facilitators interviewed during the May 2016 case study visit shared that they each support 30-35 community volunteers.

facility-based staff to facilitate support groups among program beneficiaries, including children and adolescents.

STRATEGY #3: STRENGTHEN THE HEALTH SYSTEM TO REACH VULNERABLE HOUSEHOLDS

The program’s HTS initiative, while only one component of a much larger undertaking, required a thoughtfully structured approach cognizant of cultural context of pediatric HIV infection, barriers to HIV services and pathways to successful treatment. While the program’s mandate focused on

addressing demand-side barriers, efforts to remove supply-side constraints were required. Beginning with relevant government staff, then by forming or strengthening community committees to ensure local-level decision-making and administration, the program was able to provide support exactly where it was most needed: at the HEW

The HEWs’ mandate was very broad and demanding. Yekokeb Berhan’s volunteer workforce directly assisted HEWs in fulfilling their roles, especially in regard to promoting HIV testing and facilitating access.

level. Aligning with government structures and priorities, Yekokeb Berhan intentionally supported HEWs, deploying a community volunteer workforce that extended their reach.

In Ethiopia, the HEW’s mandate included identification, referral and follow-up for clients who needed health services, including HIV testing and treatment services. However, their broad mandate and large scope of work (Table 3) made it almost impossible for them to provide the consistent, individualized support children and caregivers need to help them make and implement difficult decisions. Yekokeb Berhan’s community volunteer workforce addressed this barrier by directly assisting HEWs to fulfill their roles, especially with regard to promoting HIV testing. With the support of the volunteers, HEWs were able to function more effectively as the “hub” for health-related case management, while community volunteers served as the de facto “development army.”

The barrier created by the critical and continued shortage of HIV test kits was also addressed at several levels. While at client level, the program ensured that referred clients



Community facilitator and volunteers in Mekele, Tigray Regional State, meet regularly to ensure that the HEWs receive the support that they need.

Photo by Francesca Stuer

were assured of test kit availability before making the journey to the facility, the program established systems-level solutions as well. Implementing partners, CCCs and CCs received coaching and tools for development of partnership agreements with private clinics and NGOs⁴⁶ to provide free-of-charge HTS to program beneficiaries. While this strategy did not fully resolve the problem, it did partly redress the gap in government services.

In early 2016, under pressure to address the shortage, the MoH issued guidance to public health facilities requiring a 25 Ethiopian birr (US\$1) user-fee payment from HTS clients who were not considered to be among the “at risk populations.” The Yekokeb Berhan consortium, with other PEPFAR partners, advocated strongly with regional and national government authorities to rescind this requirement, arguing that Ethiopia would be unable to meet its 90-90-90 targets with this additional barrier in place. As a result, the MoH canceled the HTS fee charge for children and their caregivers after only a few months.

Conclusion

PROMISING PRACTICES

Within the context of a large, comprehensive HVC program, Yekokeb Berhan was able to create a workforce of HIV-literate community volunteers with an expanded role, as

Table 3: The Health Extension Program Package of Services

A. HYGIENE AND ENVIRONMENTAL SANITATION	B. DISEASE PREVENTION AND CONTROL	C. FAMILY HEALTH SERVICES
<ul style="list-style-type: none"> • Proper and safe excreta disposal system • Proper and safe solid and liquid waste management • Water supply safety measures • Food hygiene and safety measures • Healthy home environment • Arthropod and rodent control • Personal hygiene 	<ul style="list-style-type: none"> • HIV prevention and control • TB prevention and control • Malaria prevention and control • First aid 	<ul style="list-style-type: none"> • Maternal and child health • Family planning • Immunization • Adolescent reproductive health • Nutrition

46 NGO partnerships were developed with OSSA, African Service Committee, Family Guidance Association, World Wide Orphan Foundation and, recently, the USAID-funded PSI/Mulu MARPs project.

well as promote HIV testing and remove barriers to testing and treatment for children and their families. The program demonstrated that HVC program volunteers can serve both the health care and social welfare systems simultaneously and effectively to bring children to HIV testing and treatment. 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.

The Yekokeb Berhan program's system-strengthening approach and the strong association of program interventions with the government's national Health Extension Program reinforced its effectiveness and contributed to the ability of HEWs to successfully deliver their service packages. Specifically, to assist HEWs with the delicate and urgent task of identifying and referring HVC for services (including HIV testing and treatment), Yekokeb Berhan created a community volunteer infrastructure, while simultaneously strengthening the capacity of CCCs and CCs. Significantly, this alignment with key government strategies ensures that community volunteers can eventually transition to the government's community level para-professional social workforce⁴⁷ or to its "development army,"⁴⁸ and in doing so, ultimately gain access to paid employment.

Yekokeb Berhan program should be commended for their efforts to help HVC 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 HVC and their caregivers, and their successful joint advocacy with other HIV response stakeholders against the recent, short-lived government requirement that user fees be charged for HTS.

CHALLENGES AND GAPS IDENTIFIED

National policies and guidance for their implementation should facilitate a "one team" approach to enable the delivery of holistic care for children and their families. The MoH's confidentiality policy is strictly worded *and* strictly interpreted, prohibiting health care providers from disclosing a client's HIV status to community volunteers or program staff. Furthermore, not all health facilities are willing to confirm whether referred caregivers or children even presented for or received HIV testing services, and none will provide information on whether a beneficiary was linked with HIV treatment.

This is a significant constraint, forcing health centers to provide the program with key result data (the number of beneficiaries who were provided with an HIV test, the number that tested positive, and the number subsequently linked to HIV treatment) *only in the form of completely delinked data* (free of client identifiers). Thus, in order to evaluate its own performance, the program depends entirely on the ability of community volunteers to gain the confidence of caregivers and on the willingness of caregivers to disclose their family's

results. Despite this, the program was able to confirm that more than half of clients referred for testing and counseling received the service, and of clients who were tested, about 4% were seropositive.

Joint planning and agreed-upon targets for HIV testing are essential to prevent an otherwise inevitable disconnect between demand creation and supply of services. Shortage of HIV test kits has been a serious constraint to the Yekokeb Berhan program, with many referred clients encountering potentially life-threatening delays and even complete failure to access HIV testing. Clearly, achievement of the PEPFAR/UNAIDS 90-90-90⁴⁹ targets is possible *only* if a) at-risk individuals are mobilized to present for testing, and b) the demand for testing is met with adequate supply of trained service providers and testing supplies. Reliance on PITC alone will not achieve the level of coverage needed to reduce mortality and stem the tide of new infections. Community-based programs like Yekokeb Berhan are well-placed to screen and motivate clients to undertake testing, but unless these efforts are met with reliable access to clinical services, their investment of money, time and social capital will have been squandered.

Stigma remains a threat to information-sharing and care-seeking. Most respondents affirmed that stigma and discrimination experienced by people living with HIV has decreased; adults with HIV shared that they feel accepted by their communities. However, they also explained that it was still difficult to convince people to go for HIV testing, and that even once convinced, people still prefer to travel to a distant health facility to avoid recognition.

Children with HIV, on the other hand, shared that they face stigma and bullying from other children in their communities. During a focus group with children and caregivers in Gondar, children shared stories of rejection and harassment by other children. They explained that while school is a safe place where they are generally able to keep their status confidential, they worried that people in their communities suspect they might be positive because they take medicines, and make regular trips to the health facility. The adult discussants confirmed that this reality has a direct impact on the uptake of HIV testing for children, describing that adults fear their children might not cope with the anticipated scapegoating, bullying, anxiety and isolation. Some shared that their children repeatedly requested that they move to live in another location, where they could make a fresh start. Caregivers observed that stigma originates with parents who

Community-based programs like Yekokeb Berhan are well-placed to screen and motivate clients to undertake testing, but unless these efforts are met with reliable access to clinical services, their investment of money, time and social capital will have been squandered.

47 The Ethiopian MoLSA is currently working to establish a social service workforce with para-professional social workers that are deployed at community level to support CCCs and other community structures in the provision of social services to vulnerable people.

48 Ethiopia's development army consists of community-level volunteers who are trained by the health or agriculture extension workers to facilitate local behavior change. They make regular rounds to check on neighbors, and encourage development practices such as latrine building and setting up separate cooking spaces. They are from "model families," and serve as living examples that the extension workers' messages are being heard.

49 By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

The need for public education and stigma reduction

When volunteers, CCC and CC members, HEWs and community facilitators were asked to identify the critical barriers to facilitating access to HTS for children, several identified stigma, or fear of stigma, and described caregivers' fears that children will suffer stigma and will be unable to cope. They called for the restoration of media broadcasts to promote HIV prevention and stigma reduction. They shared that in recent years, very few such messages have been aired, and that some people interpret this silence as "HIV is no longer a concern." They associate this silence with their observations of an increase in HIV risk behavior.

are concerned that their children might contract HIV from a child who "looks like" she or he might have HIV.

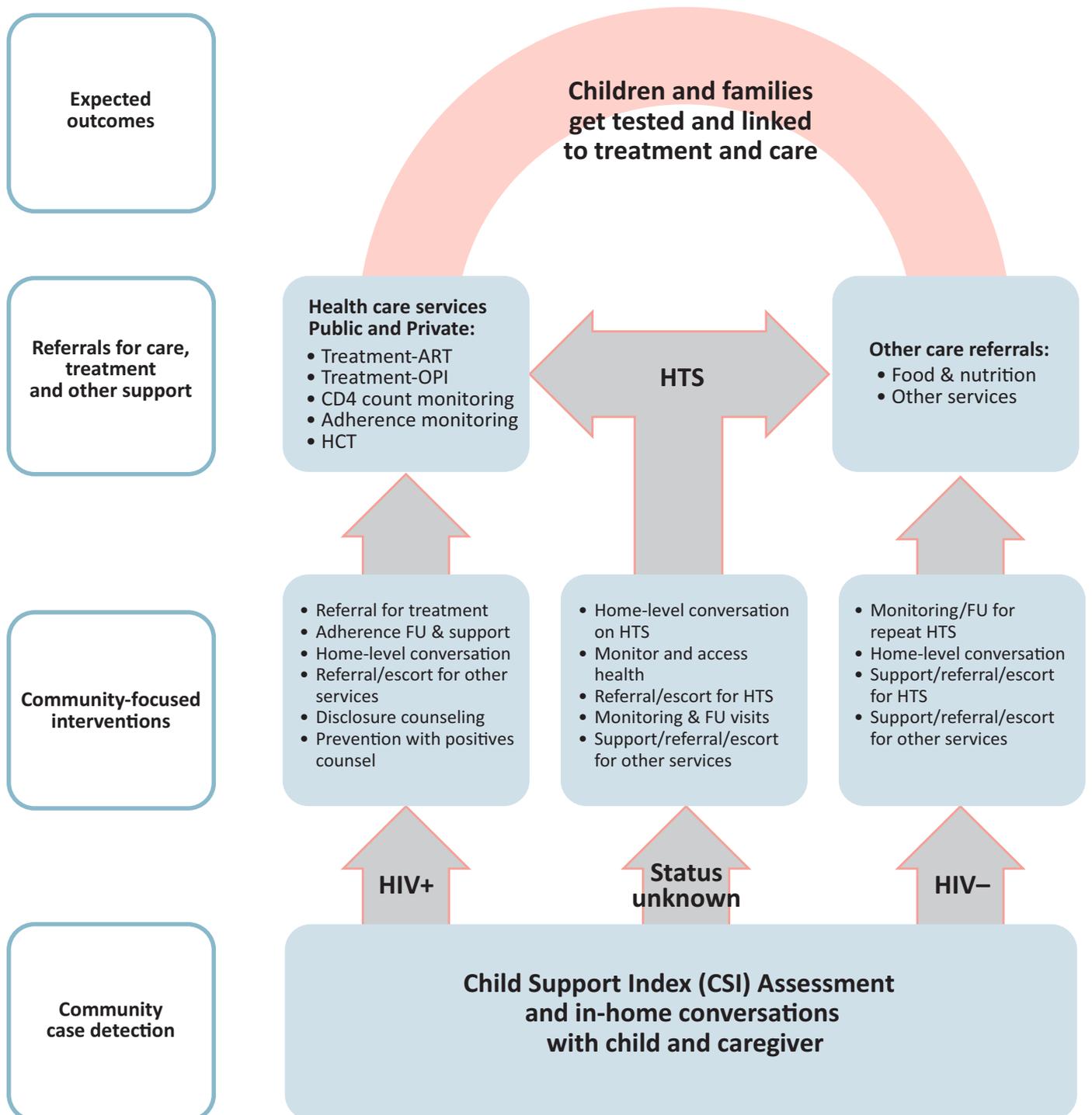
Renewed efforts to produce strategic behavior change communication programming should include a particular focus on *children living with HIV*. Specific child-to-child approaches to build compassion and caring among children at community level, e.g., through the social engagement promoted by youth groups, and household-based strategies that reduce fear and promote compassion for children living with HIV should be considered.

There is a dearth of age-appropriate support group guidelines, curricula and leadership training suitable for children living with HIV, all of which are essential to ensure that program volunteers have something to offer clients identified through HTS activities. The development of child-to-child mentorship training and "camp-style" approaches could be effective in this setting.

Approaches to better serve children who may have horizontally acquired HIV are urgently needed. Girls who have married early, victims of rape and all children who are willingly or unwillingly engaged in sexual activity need access to child-friendly HIV information and HTS.

Improved data management to provide age- and sex-disaggregated information alongside "category of service" would be instructive to future program design. It would be especially useful to understand the program's influence with PMTCT adherence, reduced loss to follow-up or improved early infant diagnosis rates.

Annex 1: Conceptual Framework for HIV Case Detection and Linkage to Treatment and Care



Yekokeb Berhan Sample Service Referral Form

Date: _____ Ref. no. _____

Name of community committee referring: _____

Name of organization referred to: _____

Contact person (referring organization): _____

Caregiver/child name: _____ ID code: _____ Age: _____ Sex: _____

Name of referring volunteer: _____

Signature: _____ Date: _____

Reasons for referral (Note: Service code in service delivery recording form will be used)

1) _____

2) _____

3) _____

Name of IP/CC responsible: _____

Signature: _____ Date: _____

Service referral feedback slip (to be filled by service providing organization)

Name of service provider organization: _____

Name of referring organization/CC: _____

Client's full name: _____ ID no. _____

Referral slip ref. no. _____ Date caregiver/child received _____

Types of service provided

1) _____

2) _____

3) _____

Services completed as requested; Yes: _____ No: _____

Follow-up needed: Yes: _____ No: _____ Date for follow-up: _____

Feedback slip filled by: _____

Position: _____ Signature: _____

Contact person (Service provider organization): _____

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.

