USAID
FROM THE AMERICAN PEOPLE

PEPFAR
U.S. President's Emergency Plan for AIDS Relief

RAPID ASSESSMENT OF PEDIATRIC HIV TREATMENT IN ZAMBIA

AIDSTAR-One
AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES

OCTOBER 2012

This publication was made possible through the support of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development under contract number GHH-I-00-07-00059-00, AIDS Support and Technical Assistance Resources (AIDSTAR-One) Project, Sector I, Task Order 1.

RAPID ASSESSMENT OF PEDIATRIC HIV TREATMENT IN ZAMBIA

AIDS Support and Technical Assistance Resources Project
AIDS Support and Technical Assistance Resources, Sector I, Task Order 1 (AIDSTAR-One) is funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development (USAID) under contract no. GHH-I-00–07–00059–00, funded January 31, 2008. AIDSTAR-One is implemented by John Snow, Inc., in collaboration with Broad Reach Healthcare, Encompass, LLC, International Center for Research on Women, MAP International, Mothers 2 Mothers, Social and Scientific Systems, Inc., University of Alabama at Birmingham, the White Ribbon Alliance for Safe Motherhood, and World Education. The project provides technical assistance services to the Office of HIV/AIDS and U.S. Government country teams in knowledge management, technical leadership, program sustainability, strategic planning, and program implementation support.

Recommended Citation
Greeson, Dana, Bisola Ojikutu, Heather Pitorak, Howard Cabral, and Ellen Cooper 2012. *Rapid Assessment of Pediatric HIV Treatment in Zambia*. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.

Abstract
Early access to antiretroviral therapy (ART) is particularly important for HIV-infected children, whose underdeveloped immune systems are more vulnerable to opportunistic infections as well as common childhood illnesses. With pediatric and adult ART coverage rates at 26 and 84 percent, respectively, Zambia demonstrates the widest gap between adult and pediatric ART coverage in high prevalence countries. In August and September of 2011, AIDSTAR-One conducted a rapid assessment of pediatric HIV treatment scale-up in Zambia to better understand the barriers to providing and/or expanding high quality pediatric HIV care and treatment services. The Zambian Ministry of Health selected 17 pediatric ART sites across five provinces for the assessment. AIDSTAR-One performed a desk review and developed a Site Assessment Tool, Walk-through Checklist, and Community Liaison Interview Guide. Analysis of the data collected in the AIDSTAR-One tools and provided by implementing partners highlights the most prominent barriers to the provision of quality pediatric HIV treatment. These include continued use of stavudine in standard first-line regimens, challenges in diagnosing treatment failure, human resources constraints, lack of caregiver involvement, lack of disclosure, limited adolescent-specific care, dysfunctional laboratory systems, and inadequate data management systems. Recommendations for mitigating these barriers and improving the quality of pediatric HIV care and treatment are offered.

Acknowledgments
The authors would like to thank the following agencies for providing input and guidance in the development of this assessment: the U.S. Agency for International Development (USAID)/Washington, USAID/Zambia, the Zambian Ministry of Health, the Center for Infectious Disease Research in Zambia (CIDRZ), the U.S. Centers for Disease Control and Prevention, Zambia HIV/AIDS Prevention, Care and Treatment II, AIDSRelief, and the Churches Health Association of Zambia. The authors would also like to thank Benjamin R. Phelps (USAID) of the U.S. President's Emergency Plan for AIDS Relief Treatment Technical Working Group, Joy Manengu (USAID/Zambia), Carolyn Bolton (CIDRZ), Peggy Bubala (CIDRZ), and all of the respondents who participated in the assessment.

AIDSTAR-One
John Snow, Inc.
1616 Fort Myer Drive, 16th Floor
Arlington, VA 22209 USA
Phone: 703-528-7474
Fax: 703-528-7480
E-mail: info@aidstar-one.com
Internet: aidstar-one.com

CONTENTS

ACRONYMS

ALHIV	adolescents living with HIV
ART	antiretroviral therapy
ARV	antiretroviral
AZT/3TC	zidovudine/lamivudine
CBO	community-based organization
CDC	U.S. Centers for Disease Control and Prevention
CHAZ	Churches Health Association of Zambia
CIDRZ	Center for Infectious Disease Research in Zambia
CTX	cotrimoxazole
d4T	stavudine
DBS	dried blood spot
DHMT	District Health Management Team
EFV	efavirenz
INH	isoniazid
LPV/r	lopinavir/ritonavir
MOH	Ministry of Health
NNRTI	non-nucleoside reverse transcriptase inhibitor
NRTI	nucleoside reverse transcriptase inhibitor
NVP	nevirapine
PCR	polymerase chain reaction
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission
TB	tuberculosis
WHO	World Health Organization
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNZA REC	University of Zambia Biomedical Research Ethics Committee
USAID	U.S. Agency for International Development
ZPCT II	Zambia Prevention, Care and Treatment II

EXECUTIVE SUMMARY

Antiretroviral therapy (ART) has averted an estimated 2.5 million deaths in resource-limited settings since 1995 (World Health Organization [WHO] 2011a). Early access to antiretrovirals is particularly important for HIV-infected children, whose naturally underdeveloped immune systems increase their vulnerability to opportunistic infections as well as common, but severe, childhood illnesses. Zambia faces a generalized HIV epidemic with a prevalence of 13.5 percent among adults aged 15 to 49. Approximately 980,000 people in Zambia are living with HIV, including 120,000 children (Joint United Nations Programme on HIV/AIDS 2009). As is the case globally, a disparity exists between pediatric and adult ART coverage in Zambia. With pediatric and adult ART coverage rates at 26 and 84 percent, respectively, Zambia demonstrates the widest gap between adult and pediatric ART coverage in high prevalence countries (WHO 2011a).

Following the WHO's 2010 revision of *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access*, the Zambian Ministry of Health (MOH) released a national adaptation, *Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia*. The revised national guidelines call for improved pediatric HIV treatment through measures such as initiating all HIV-positive children less than two years of age on treatment, irrespective of clinical or immunological status (Republic of Zambia MOH 2010).

In August and September of 2011, AIDSTAR-One conducted a rapid assessment of pediatric HIV treatment scale-up in Zambia to better understand the barriers to providing and/or expanding high quality pediatric HIV care and treatment services throughout the country. AIDSTAR-One worked in collaboration with the Zambian MOH, U.S. Agency for International Development/Zambia, and the Center for Infectious Disease Research in Zambia to conduct this assessment. The U.S. Centers for Disease Control and Prevention simultaneously implemented a protocol to evaluate early infant diagnosis systems in Zambia. The report from that evaluation serves as a complement to this report.

The Zambian MOH used stratified, purposive sampling to select 17 pediatric ART sites across five provinces for the assessment). The study protocol and assessment tools were submitted to the University of Zambia Biomedical Research Ethics Committee and approved in April 2011. AIDSTAR-One performed a desk review and developed a Site Assessment Form and Walk-through Checklist for administration at the 17 sites and a Community Liaison Interview Guide used in key informant interviews at associated District Health Management Team offices.

AIDSTAR-One facilitated a two and a half day training session with seven local data collectors, including a pilot at three sites in Lusaka, prior to splitting into groups for travel to the other provinces. In concordance with MOH protocol, teams visited provincial and district medical officers in each location to explain their goals and to seek permission for site visits. The major themes discussed during site visits were human resources, treatment guidelines, ART eligibility and initiation, adolescent services, adherence, nutrition, community engagement, and pharmacy and laboratory services.

Analysis of the data collected in the AIDSTAR-One tools and provided by implementing partners highlights the most prominent barriers to providing quality pediatric HIV treatment. These include:

- Continued use of stavudine (d4T) in standard first-line pediatric regimens at many facilities
- Challenges in diagnosing treatment failure in pediatric patients
- Persistent human resource constraints
- Poor retention of adherence support workers and community health workers due to lack of compensation
- Lack of caregiver involvement
- Lack of pediatric and adolescent disclosure
- Limited availability of targeted care, treatment, and support programs for adolescents
- Dysfunctional laboratory systems (i.e., frequent machine breakdowns and reagent stockouts)
- Inadequate data management systems.

Recommendations for mitigating these barriers and improving the quality of pediatric HIV care and treatment are summarized as follows.

- Transition from the use of d4T in standard first-line regimens; improve access to nevirapine (NVP) alternatives for children who have been exposed to single-dose NVP; improve identification of treatment failure and immune reconstitution inflammatory syndrome.
- Improve communication and accountability as a step in reducing heavy workload for staff.
- Where hourly wages are not feasible, efforts should be made to provide volunteers with the supplies they need to conduct their tasks and a transportation allowance.
- Develop a mentor caregiver initiative whereby attentive (non-parental) caregivers mentor those who are struggling, through psychosocial support and advice.
- Follow guidance on the disclosure process using tools such as the International Center for AIDS Care and Treatment Programs' *Adolescent HIV Care and Treatment: A Training Curriculum for Multidisciplinary Health Care Teams*, which was created specifically for Zambia. Module 7 is on "Providing Disclosure Counseling and Support." AIDSTAR-One is also developing tools on disclosure.
- More clinics should consider targeting services to the increasing population of adolescents living with HIV. Clinics with well-established programs for this group can share information with those interested in starting one. In addition, AIDSTAR-One is developing guidance materials and tools on this topic.
- There is a need for more laboratory technicians and technologists, and it may be worth offering incentives for entering this field if this is not already being done. A plan to diagnose the cause of machine breakdowns and reagent stockouts and to prevent their frequent occurrence are crucial steps in improving HIV treatment.
- Continued technical assistance and capacity building in the area of data collection.

BACKGROUND

PEDIATRIC HIV AND TREATMENT

Antiretroviral therapy (ART) has averted an estimated 2.5 million deaths in resource-limited settings since 1995 (World Health Organization [WHO] 2011a). Combination ART has revolutionized the HIV epidemic by increasing the lifespan of people living with HIV, enhancing quality of life, and decreasing transmission rates by reducing viral load. HIV treatment is no longer universally synonymous with daily pill burden and harsh side effects. Fixed dose combinations—two or more active antiretrovirals (ARVs) combined in a single fixed dose—have improved ART adherence through decreased pill burden, more manageable dosing schedules, and fewer side effects and interactions.

Several global initiatives have set goals to expand ART coverage among those populations most vulnerable to HIV. In 2003, the WHO and the Joint United Nations Programme on HIV/AIDS' (UNAIDS') "3 by 5" initiative aimed to reach three million people worldwide with ART by the end of 2005. When the initiative began, only 400,000 people were on ARVs globally. The goal of reaching three million people was eventually achieved in 2007. By the end of 2010, 6.65 million people were on ART (WHO 2011a). In 2000, the United Nations Millennium Development Goals were developed. Goal 6B aimed to achieve universal access to HIV treatment for persons in need by 2010. The impetus for the inclusion of this goal was due to infections continuing to surpass treatment scale-up, and evidence indicating that treatment expansion for HIV-positive women of childbearing years could also protect their babies (United Nations Millennium Development Goals n.d.).

Between 2007 and 2010, the global number of clinical care facilities providing ART tripled (from 7,700 to 22,400), and ART coverage increased 16-fold from 2003 to 2010 (WHO 2011a). Despite this commendable scale-up effort, less than half of the people eligible for treatment were accessing ARVs by the end of 2010. In 2009, the number of children (under 15 years of age) living with HIV reached 2.5 million (UNAIDS 2010). While global adult ART coverage is 51 percent, ART coverage for children is at only 23 percent (456,000 children). The disparity between pediatric and adult ART coverage has been associated with complicated diagnostics and weight-based dosing, a rigorous cascade of care, unavailability of pediatric ART formulations, and the later implementation of pediatric HIV programs and drug regimens in health facilities. Concerning attrition rates along the entire pediatric cascade of care emphasize the importance of additional community supports and linkages within the health system (WHO 2011a).

Early access to ARVs is particularly important for HIV-infected children, whose naturally underdeveloped immune systems increase their vulnerability to opportunistic infections as well as common, but severe, childhood illnesses. Without early diagnosis and treatment, approximately one-third of HIV-infected infants will die before their first birthday and almost half before their second birthday. Appropriate diagnostics and treatment coupled with strong adherence make it possible for HIV-infected infants to reach adolescence and adulthood (WHO 2011a).

PEDIATRIC HIV AND TREATMENT IN ZAMBIA

Zambia faces a generalized HIV epidemic with a prevalence of 13.5 percent among adults aged 15 to 49. Approximately 980,000 people in Zambia are living with HIV, including 120,000 children (UNAIDS 2009). With an estimated overall ART coverage of 72 percent, Zambia is close to attaining universal access, which is defined as providing ART to at least 80 percent of those eligible (WHO 2011a). Although significant strides have been made in increasing access to treatment, a disparity exists between pediatric and adult ART coverage in Zambia. With pediatric and adult ART coverage rates at 26 and 84 percent, respectively, Zambia demonstrates a significant gap between adult and pediatric ART coverage in high prevalence countries (WHO 2011a). With an estimated 98,000 children in Zambia eligible for ART, less than 26,000 have initiated therapy (WHO 2011a). There is heightened emphasis on increasing ART coverage among children living with HIV in Zambia. In addition, providers and policymakers are beginning to consider strategies designed to address the unique psychosocial and treatment needs of adolescents living with HIV (ALHIV; Republic of Zambia Ministry of Health [MOH] 2010).

ZAMBIA'S 2010 PEDIATRIC ART GUIDELINES

Following the WHO's 2010 revision of *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access*, the Zambian MOH released a national adaptation, *Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia.* According to the guidelines, the MOH aims to achieve over 95 percent ART coverage for eligible infants and children by the end of 2015 (Republic of Zambia MOH 2010). Strategies to reach this goal include:

1. Decentralizing pediatric HIV care to the primary health care level
2. Strengthening intra- and inter-facility referral systems
3. Reducing lab turnaround time through improved courier systems for all specimens and innovations including SMS (short message service or text message) technology
4. Building health care worker capacity to provide pediatric HIV care through mentorships and trainings
5. Implementing the "Family-Centered Approach" in all facilities by December 2012
6. Strengthening district level management and coordination of pediatric care activities
7. Improving patient retention through community engagement and early diagnosis and ART initiation (Republic of Zambia MOH 2010).

Specific recommendations in the 2010 Republic of Zambia MOH national guidelines include:

- Earlier, more accurate diagnosis: HIV exposure status should be determined at birth or soon thereafter; early infant diagnosis should be performed by four to six weeks of age.
- Earlier initiation of ART: all HIV-positive children less than two years of age should start immediately on ART.
- Children two years of age and above with WHO pediatric clinical stage three or four should be initiated on ART irrespective of CD4 count. Immunological criteria for children aged two to five to initiate ART is a CD4 percentage less than or equal to 25 percent or a CD4 count less than or

equal to 750 cells/mm^3. Immunological criteria for children five years of age and older is a CD4 count less than or equal to 350 cells/mm^3.

- First- and second-line regimens should be simplified: encourage fixed dose combinations. Use protease inhibitors for infants exposed to a non-nucleoside reverse transcriptase inhibitor (NNRTI). Recommend preferred standard regimens.
  - Preferred nucleoside reverse transcriptase inhibitor (NRTI) backbone: zidovudine/lamivudine (AZT/3TC).
    - Children under two years of age with no previous NNRTI exposure should use nevirapine (NVP).
    - Children under two years of age with previous NNRTI exposure should use lopinavir/ritonavir (LPV/r) to complete the regimen.
    - Children between two and three years of age should use NVP as the third drug and children aged three and older can use NVP or efavirenz (EFV) as the third drug (*refer to guidelines for specifics and exceptions).*
- Improved understanding of signs and symptoms to expect in the first six months of treatment.
- Additional attention to the nutritional needs of children on treatment.
- Enhanced monitoring for ART efficacy and toxicity: improved laboratory monitoring, a simple guide to routine clinical follow-up, and a phased-in approach to viral load testing.
- Cotrimoxazole (CTX) for HIV-positive children, as follows:
  - Under 24 months of age: start CTX regardless of CD4 or clinical stage.
  - From 24 to 59 months of age: start CTX when a) child is in clinical stage 2, 3, or 4 regardless of CD4; or b) when CD4 percent is less than 25 percent, regardless of clinical stage.
  - Five years of age and above: start CTX when a) child is in clinical stage 2, 3, or 4 regardless of CD4; or b) when CD4 count is less than 350 cells/mm^3, regardless of clinical stage.
- Strengthening adherence.

METHODOLOGY

In August and September of 2011, following the release of Zambia's updated national treatment guidelines in March 2010, AIDSTAR-One conducted a rapid assessment of pediatric HIV treatment scale-up in Zambia to better understand the barriers to providing and/or expanding high quality pediatric HIV care and treatment services. The assessment was funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development (USAID). AIDSTAR-One worked in collaboration with the Zambian MOH and USAID/Zambia. The Center for Infectious Disease Research in Zambia (CIDRZ) provided local expertise. The U.S. Centers for Disease Control and Prevention (CDC) simultaneously implemented a protocol to evaluate early infant diagnosis systems in Zambia. The report from that evaluation serves as a complement to this report.

OBJECTIVES

The goals of this assessment were to:

1. Identify barriers and facilitators to the delivery of high quality pediatric and adolescent HIV care and treatment services in Zambia.
2. Assess whether treatment sites are using the 2010 national pediatric guidelines, and document barriers and facilitators of guideline implementation.
3. Assess available and necessary resources to implement and expand pediatric treatment services.
4. Document successful models of community engagement, which have increased access to pediatric care and treatment.

The study protocol and assessment tools used in the assessment were submitted to the University of Zambia Biomedical Research Ethics Committee (UNZA REC) and approved in April 2011.

SAMPLING

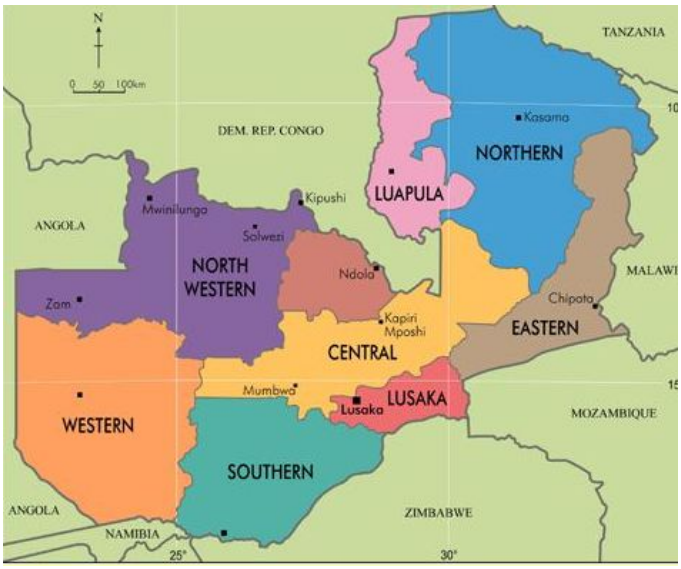
The MOH used stratified, purposive sampling to select 17 pediatric ART sites across five provinces for the assessment (see Table 1). The criteria guiding site selection included geographic location (see Figure 1), setting (i.e., urban, peri-urban, or rural), site type (i.e., primary, secondary, and tertiary hospitals, and urban and rural health centers), and facility size. Although all sites are MOH sites, they vary in terms of implementing partner support; some sites have none, whereas others are supported by CIDRZ; Zambia Prevention, Care and Treatment II (ZPCT II); AIDSRelief; or the Churches Health Association of Zambia (CHAZ).

Table 1. Site Characteristics

Province	District	Site	Site Type	Setting	Partner	Number of Pediatric ART Patients in 2010*
Copperbelt	Kitwe	1. Buchi Main Health Center	Urban Health Center	Urban	ZPCT II	43
		2. Bulangililo Health Center	Urban Health Center	Urban	ZPCT II	25
	Masaiti	3. Masaiti Boma	Health Post	Rural	n/a	15
		4. Mishikishi Health Center	Health Post	Rural	CHAZ	31
	Ndola	5. Arthur Davidson Hospital	Tertiary Hospital	Urban	ZPCT II	1,641
Luapula	Mansa	6. Mansa General Hospital	Secondary Hospital	Urban	ZPCT II	231
		7. Chembe Health Center	Rural Health Center	Rural	ZPCT II	10
		8. Senama Health Center	Urban Health Center	Urban	ZPCT II	37
	Kawambwa	9. Kwambwa District Hospital	Primary Hospital	Rural	ZPCT II	59
Lusaka	Lusaka	10. University Teaching Hospital	Tertiary Hospital	Urban	n/a	2,271
		11. Kalingalinga Clinic	Urban Health Center	Urban	CIDRZ	435
		12. Kanyama Clinic	Primary Hospital	Urban	CIDRZ	971
Southern	Choma	13. Macha Mission Hospital	Primary Hospital	Rural	AIDSRelief	1,881
		14. Shampande Rural Health Center	Urban Health Center	Peri-urban	CIDRZ	30
Western	Sesheke	15. Yeta District Hospital	Primary Hospital	Urban	CIDRZ	219
	Mongu	16. Lewanika General Hospital	Secondary Hospital	Urban	CIDRZ	699
		17. Sefula Rural Health Center	Health Post	Rural	CIDRZ	50

* Patient numbers gathered from sites and/or implementing partners.

Figure 1. Map of Zambian Provinces



Source: Republic of Zambia Ministry of Mines and Mineral Development n.d.

DESK REVIEW

Prior to developing assessment tools, AIDSTAR-One conducted a comprehensive review of key program documents, including national guidelines and relevant treatment protocols, national and site program data, reports, and abstracts. National, implementing partner, and site staff were interviewed to provide contextual data and "grey literature," including any additional reports and internal documents as available. Medical literature was reviewed for pertinent published documents to continue to guide the assessment design.

ASSESSMENT TOOLS

AIDSTAR-One developed the following three assessment tools for this assessment. In this report, results from these tools are summarized in the form of frequency counts and percentages. Common themes from qualitative responses from the Site Assessment Tool and the Community Liaison Interview Guide were identified.

1. SITE ASSESSMENT TOOL

The Site Assessment Tool contains questions aimed at various health care providers regarding services for HIV-infected children (i.e., medical and clinical officers, pediatric HIV nurses, laboratory technologists or technicians, and pharmacists or pharmacy technicians). Topics covered in the assessment form include: human resources, nutrition, treatment guidelines, community engagement, ART eligibility and initiation, pharmacy services, adolescent services, laboratory services, and adherence. Data collectors were instructed to read the informed consent paragraph (printed at the beginning of each section) each time they spoke with a new respondent. In order to maintain anonymity, the data capturer signed the informed consent on the respondent's behalf once verbal consent was given.

2. WALK-THROUGH CHECKLIST

The Walk-through Checklist was designed for data capturers to observe service provision and note various resources. The goal was to determine the resources and space available to pediatric HIV providers and patients. Topics include basic resources (i.e., water, electricity, and telephone), decision aids, pediatric equipment, and "pediatric friendly" physical space.

3. COMMUNITY LIAISON INTERVIEW GUIDE

A short interview guide was used with the district community liaisons, who oversee health-oriented community-based organizations (CBOs) within each District Health Management Team (DHMT). The interview guide focuses on CBOs providing support to HIV-infected children and their families and includes topics such as referral systems, follow-up of patients, gaps in community services, and the potential for service expansion. Thematic analysis was used to interpret interview transcripts.

SITE-LEVEL AGGREGATE PROCESS AND OUTCOMES DATA

In order to augment results from the site level survey tools, AIDSTAR-One requested that implementing partners provide site-level aggregate data on patient outcomes and several process indicators for enrollment cohorts from 2007 through 2010. Nine of the seventeen sites were able to provide aggregate data. This data is presented throughout this report where appropriate and is available in Appendices A and B. In some cases, associations between process and clinical outcomes variables were able to be correlated with variables from the Site Assessment Tool (see Appendices C and D). Associations were estimated using odds ratios with 95 percent confidence intervals and p-values. Results with p-values less than 0.05 were considered statistically significant. All analyses were conducted using SAS version 9.2 (SAS Inc., Cary, NC).

TRAINING AND PILOT

Prior to data collection, AIDSTAR-One facilitated a two and a half day training session with seven local data collectors in Lusaka, Zambia. Five of the seven data collectors were nurses who were trained in and delivered HIV care, whereas the remaining two had experience working on HIV programs and studies. Training curriculum reviewed pediatric HIV and treatment in the global and Zambian contexts and covered assessment objectives, methodology, and logistics. Assessment tools were reviewed in detail.

On the second training day, the group divided into three teams and visited three separate pediatric ART facilities in Lusaka to pilot the tools. The following day, teams regrouped to discuss lessons learned, seek clarification of objectives and methodology, provide feedback, and give input into the revision of the tools. Teams departed for the provinces the next day.

PROVINCIAL AND DISTRICT HEALTH OFFICE INTRODUCTIONS

In concordance with MOH protocol, teams visited provincial and district medical officers in each location to explain their goals and seek permission for site visits. Teams presented approval letters from the MOH and UNZA REC, the study protocol, the information sheet describing the

assessment, and the assessment tools. District medial officers provided points of contact for assessment sites in their regions. In addition, during these visits, interviews with the district community liaisons were conducted as their availability allowed. Teams returned to the provincial and district health offices to debrief on site visits by request, and several provincial and district medical officers mentioned their desire to receive the assessment results which they felt could help inform pediatric HIV programs at their sites.

ON-SITE RAPID ASSESSMENTS

Upon arrival at each site, team members introduced themselves to the designated contact person and presented them with the MOH and UNZA REC approval letters and the assessment information sheet. The point of contact introduced teams to the appropriate respondents for the site assessment. All teams did their best to be flexible with the respondents' schedule so as to minimize the interruption of patient care and to be respectful of the time of each of the respondents. Following introductions and explanations of the aforementioned forms to the respondent, an AIDSTAR-One team member read the informed consent and the respondent provided verbal consent. One team member read the questions aloud, while another wrote the answers on a separate copy of the form. The third team member conducted the Walk-through Checklist while the interviews occurred. Prior to leaving the sites, team leaders reviewed the Site Assessment Form and Walk-through Checklist to ensure clarity and completion. After the site visits, team leaders entered the data into a Microsoft Access Database (Microsoft, Inc., Redmond, WA).

LIMITATIONS

This assessment has a number of limitations. The sample size utilized is small and was limited to five of the nine Zambian provinces. Only 9 of the 17 sites provided site-level process and outcomes data. In addition, human resource constraints in Zambia are pervasive throughout the health care system. Therefore, collecting data from providers was challenging. Data collectors were instructed to be cognizant of providers' workloads and to be flexible in scheduling meeting times. In some cases, the optimal person to speak with at the facility was unavailable. Because data collectors had a limited number of days in each district, they captured data from alternate individuals. Although these limitations exist, this report provides some insight into pediatric treatment challenges in Zambia. A larger study would be necessary to ensure the ability to generalize.

FINDINGS

HUMAN RESOURCES

Human resource constraints are well recognized across health care systems in resource-limited settings, and Zambia is no exception. Ten sites (59 percent) reported that retention of staff is a problem within their pediatric HIV program. The most commonly reported reasons for staff departure were personal choice (reported by nine sites) and standard reassignment (eight sites). Retirement, transferring to a private clinic, and professional development opportunities were the most common explanations for choosing to leave a clinic post.

STAFF TRAINING

In light of high staff turnover and changes to pediatric treatment protocols, trainings are an important means of keeping staff informed of best practices in providing quality treatment to pediatric HIV patients. Sites were asked whether specific topics had been covered in trainings attended by pediatric HIV staff members. Responses are presented in Table 2.

Table 2. Training Topics Covered at Sites

Training Topic	Number of Sites with Topic Included in Training for Pediatric HIV Staff
Growth and nutrition assessment	12 (71%)
Physical examination	15 (88%)
Assessing developmental progress	10 (59%)
Ongoing ART eligibility assessments for HIV-infected children not yet on ART	12 (71%)

Sites were enthusiastic about trainings and recommended that more facility staff members, such as those in the maternity and outpatient departments, attend HIV trainings so that they could assist when HIV staff is unavailable or overwhelmed. Sites also requested refresher courses when practices have changed or when a specific topic has not been addressed for some time.

Twelve sites reported that clinical mentoring is offered to pediatric HIV staff. Of those, 10 sites rated the clinical mentoring as very effective. Two sites rated it moderately effective, and one expressed the need for greater continuity within the mentoring program.

GUIDELINES AND PROTOCOLS

Sixteen sites (94 percent) reported following Zambia's 2010 guideline recommendations in their entirety, although further inquiry revealed numerous challenges to adhering to the guidelines. Most sites reported initiating all HIV-infected children less than two years of age on ART irrespective of immunological status (15 sites; 88 percent) and measuring adherence at each visit (16 sites; 94 percent). Four sites (24 percent) reported not using clinical staging to initiate treatment over the age

of two when CD4 testing is unavailable, despite guideline recommendations to do so. Qualitative responses indicated that health care providers lacked confidence regarding eligibility criteria for children aged two to five. The most commonly identified reason for failure to start ART was a lack of trained health care providers onsite to initiate treatment. Of note, all but one site reported that pediatric HIV patients must have a designated caregiver prior to ART initiation.

Seven sites (41 percent) continue to use NVP in first-line regimens for NVP-exposed infants because LPV/r or other guideline-approved alternatives are not available. Ten sites (59 percent) continue to use stavudine (d4T) in first-line regimens, although several reported that they are in the process of transitioning with some waiting until their d4T stock runs out. Only one site reported the use of isoniazid (INH) prophylaxis among tuberculosis-exposed children, as recommended in the guidelines. Challenges to guideline implementation included laboratory limitations, drug availability, and human resource deficits.

HIV CARE (PRE-ART)

All sites reported providing the following services to pre-ART pediatric patients: clinical care, opportunistic infection prophylaxis (CTX), nutrition counseling, and psychosocial support and counseling. The main challenges that sites identified in caring for pre-ART patients were: 1) delays in patient return to the clinic, 2) a lack of supplementary food available at clinics and CBOs, and 3) loss to follow-up. Providers speculated that losses to follow-up may be more common among pre-ART patients. In addition, providers reported that caregivers tend to wait until children have symptoms of disease progression before returning to the clinic.

TREATMENT OUTCOMES

Nine sites provided site-level aggregate data representing 12,792 pediatric patients, of which 3,670 (29 percent) had been initiated on ART. Forty-nine percent of pediatric patients on ART were initiated within four weeks of eligibility. Of the sites providing enrollment data, 35 percent of children were eligible for ART (eligibility determined by national guidelines in place at the time of initiation) and 76 percent of those children were initiated on ART (see Appendix A). This pediatric ART coverage rate is significantly higher than the national coverage rate of 26 percent as noted by the WHO.

Outcomes data for the period of 2007 through 2010 were provided for nine sites (see Table 3). Seventy-four percent of pediatric patients were alive and in care at the end of this period. According to the site-level data, an average of five percent of initiated children had failed treatment from 2007 to 2010. Thirty-two percent of these children were prescribed second-line therapy (see Appendix A). Information regarding the remaining 68 percent was not available. It can be speculated that some may have died or defaulted, or that perhaps some facilities did not have the appropriate second-line regimens available. It is important to note the possibility of undiagnosed treatment failure due to limited access to viral load testing and treatment experts. The majority of sites (11) refer patients with suspected treatment failure to specialist centers at outside facilities. Five sites reported that a treatment expert comes to the site on a regular basis, and four sites were specialist centers themselves.

Table 3. Patient Outcomes at Selected Sites from 2007 to 2010

	Number of Patients	Percentage
Alive	2,715	74%
Dead	171	5%
Lost to follow-up	516	14%
Transferred	268	7%
Total	3,670	100%

See Appendix B for detail by site.

Reported barriers to the provision of pediatric ART were a shortage of trained staff, drug stockouts, lack of space, failure of caregivers to take referred patients to specialist centers (sometimes due to transport costs), inability to perform viral load tests, and malnutrition, which sites felt was especially prevalent among orphans. Sites were most encouraged by the general improvements in the health of their patients as advances in pediatric ART continue to be implemented at the site level.

From 2007 to 2010, the mean loss to follow-up rate was 14 percent for ART patients at sites providing data (Table 3). Respondents were asked how their sites defined defaulters within the pediatric HIV clinic. The most common definition given was "greater than three months late for the last scheduled appointment." Sixteen sites reported having a system in place to identify defaulters, whereas 13 also had a system to locate them. Sites used a combination of registers, patient files, and SmartCare to identify defaulters. SmartCare is an electronic health records system developed by the MOH in collaboration with the CDC to improve health information systems from the patient to the national level. Five sites reported having both internal and external Quality Improvement Teams. Most sites have a protocol in place whereby adherence counselors call or SMS (text message) patients/caregivers after a missed visit. If this fails, adherence counselors use the patient locator form containing patient addresses and maps to locate the patient at his or her home.

Some of the most common challenges reported in locating defaulters were wrong addresses given by patients/caregivers and a lack of transport and supplies for adherence support workers, especially during the rainy season when boots, raincoats, and umbrellas are necessary. Missed visits are more common in the rainy season, especially for those patients living far from the site. It is difficult for adherence support workers to travel long distances to follow up with these patients in their communities. Finally, adherence support workers reported a lack of incentive because the majority of them work on a voluntary basis and do not have the necessary supplies to do the job effectively. In light of human resources and funding constraints, the health care system relies heavily on unpaid staff such as adherence support workers and community health workers.

MONITORING AND EVALUATION

All but one site used electronic medical records, predominantly SmartCare. Five sites reported having both internal and external Quality Improvement Teams. Seven sites reported having only an internal team, whereas three reported only an external team. One site reported not having a Quality Improvement Team. Nine sites responded that trainings had been conducted around issues of quality assessment and quality improvement within the pediatric HIV program.

SERVICE DELIVERY MODELS

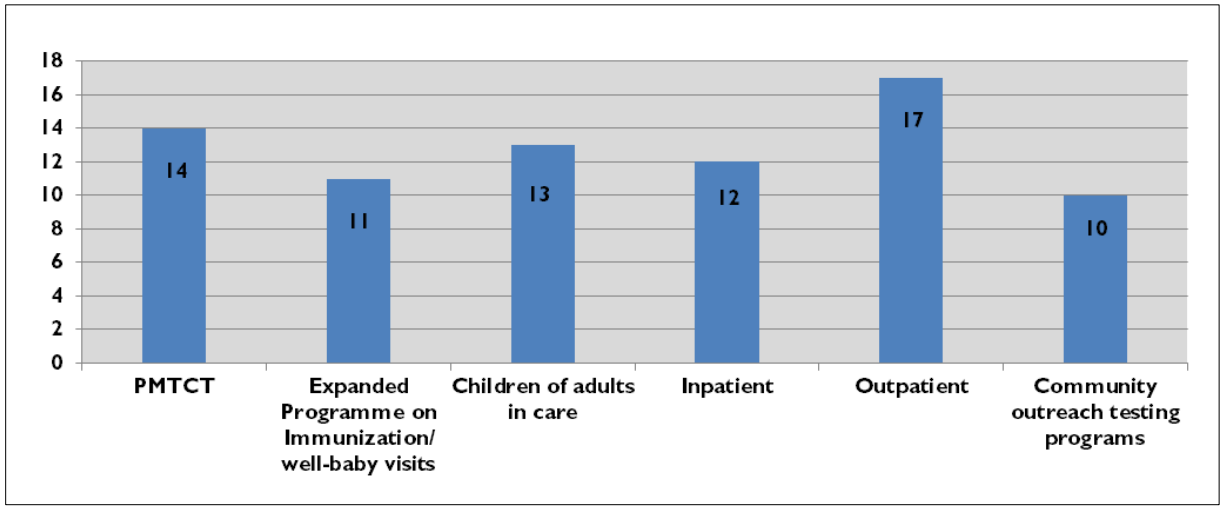
Service delivery models varied across sites. Eleven sites reported seeing pediatric and adult ART patients during the same time in the same place. Five sites reported using the same space to see pediatric and adult ART patients, but at different times. The remaining site was part of a tertiary children's hospital and only provided care to pediatric patients.

The use of mobile clinics has increased in Zambia as facilities recognize the increased need for access to care and treatment. Nine sites provide some pediatric services through mobile clinics. Testing and counseling (including dried blood spot [DBS] testing) were the pediatric HIV services offered most frequently though mobile clinics, followed by clinical staging and ART follow-up. Six sites reported providing CD4 testing, ART initiation, and drug dispensation (including ARVs) through mobile clinics.

All sites reported that the Government of Zambia covers the cost of HIV services, including appointments, medications, and laboratory costs. The one exception was that some sites that referred patients to outside laboratories for liver function tests reported that patients were charged a fee by the lab that was often prohibitive.

Access to pediatric HIV testing and counseling is crucial for timely treatment to occur, especially given children's increased vulnerability to opportunistic infections due to underdeveloped immune systems. HIV-positive children who have not been diagnosed are typically seen in clinics other than the HIV clinic for wellness visits, illnesses, or prevention of mother-to-child transmission (PMTCT)-related care. It is therefore important that pediatric testing is accessible in various clinics within a facility. Respondents were asked whether pediatric HIV testing was available in a variety of service areas at their site (see Figure 2). The outpatient department was the only service identified by all sites as providing pediatric HIV testing.

Figure 2. Number of Sites Offering Pediatric Testing and Counseling by Service



Sites were also asked about the most common way that HIV-infected children enter into HIV care. The most common response, as reported by 12 sites, was PMTCT.

ADOLESCENT SERVICES

Advances in pediatric HIV treatment have led to a growing number of perinatally infected children reaching adolescence. The growing number of ALHIV has resulted in increased advocacy for this group and recognition of their unique care and treatment needs. Although the WHO defines the adolescent age range as between 10 and 19 years of age, many assessment sites based decisions on whether to transition pediatric patients to adult services on physical and cognitive development instead of age. The median age range across sites for adolescent care was 12 to 19. Some people living with HIV may remain in pediatric or adolescent services beyond 19 years of age. The decision to transition is made by the health care provider and is based on the adolescent's level of independence and evidence of developmental and cognitive delays associated with HIV.

Three sites had established a specific clinic day for ALHIV. Five sites reported seeing adolescent patients in the pediatric clinic, whereas 10 saw adolescents in the adult ART clinic. Sites were asked which of the five services listed in Table 4 were available and tailored to ALHIV. A median of three of these five services were offered per site (mean = 3.5). Tailored services most commonly offered were psychosocial support and positive prevention.

Table 4. Services Tailored to Adolescents by Site

Services Tailored to Adolescents	Number of Sites Offering Service
Family planning and contraceptives	11 (65%)
Psychosocial support	13 (76%)
Peer support groups	12 (71%)
Disclosure support	11 (65%)
Positive prevention	13 (76%)

When asked about the main challenges in treating adolescents, the most common answer was disclosure. Many adolescents have not been told about their HIV status by caregivers, despite the recommendation to begin the step-by-step disclosure process in perinatally infected children around the age of six (WHO 2011b). Adolescents who have not been disclosed to may suspect their positive status based on their daily medications and talk about HIV within their communities. "Accidental" disclosure has been associated with poor health outcomes and deteriorated relationships between patients and caregivers. Engaging children and adolescents in a step-by-step disclosure process has been shown to improve ART adherence as patients often take increased ownership of their health (WHO 2011b). Providers at sites that were able to provide tailored services to adolescents reported on the benefits of connecting ALHIV through clubs and support groups.

HIV-EXPOSED INFANTS

For 14 of the sites, the PMTCT program was the most common way that HIV-exposed infants entered into HIV care. The remaining three sites reported that the Expanded Programme on Immunization, well-baby visits, and inpatient services were the most common points of entry. Just over half of the sites (nine) reported following exposed infants within the PMTCT clinic. The remainder saw them within the HIV clinic, with the exception of one site that follows them in the under-five clinic. Providers reported that the biggest challenges in providing care to exposed infants are mothers not returning to collect DBS results and mothers giving incorrect contact information to avoid follow-up. DBS turnaround time (18 days according to averaged responses) was also

mentioned as a challenge to providing timely HIV treatment to those exposed infants who are found to be infected. For more information on this process, please see the CDC's forthcoming evaluation on Zambia's early infant diagnosis data and lab systems.

ADHERENCE

All sites reported providing pediatric patients and caregivers with adherence support counseling prior to ART initiation. Of the nine sites with site-level data, 89 percent of patients initiated from 2007 to 2010 had received adherence counseling at their last visits (see Appendix A). Nearly all sites (16) reported assessing adherence at every visit. Most sites (11) reported that using patient/caregiver report and pill count (or measuring syrup) has been an effective way to measure adherence.

Providers reported a number of ways of dealing with situations where non-adherence is suspected or detected. Some of the more common strategies were to decrease the time between patient appointments, to speak directly to the child without the caregiver present (if the disclosure process has already begun), and to provide age-appropriate counseling aimed at the patient. Nine sites reported offering treatment buddies—other than primary caregivers—to older pediatric patients. Thirteen sites use home-based or community-based initiatives as a way to promote pediatric ART adherence. Providers mentioned several barriers to pediatric ART adherence, including neglectful caregivers (especially when children are not living with a biological parent), malnutrition, and ART side effects.

TUBERCULOSIS–HIV CO-INFECTION

Tuberculosis (TB)–HIV co-infection is a significant concern among providers and caregivers of pediatric patients. Children's underdeveloped immune systems coupled with HIV-related immunosuppression make HIV-positive children extremely vulnerable to TB. The national guidelines recommend screening all HIV-infected children for TB at every visit by asking the child or caregiver about any contact with individuals known to be infected with TB and assessing for symptoms such as poor weight gain, recurrent cough, or fever. All but one site reported screening each pediatric HIV patient for TB as per guidelines at the initial visit to the HIV clinic. Those determined to be at high risk for TB were sent for chest X-rays (sometimes at a referral site) or sputum samples were obtained depending on their age. More than half of the sites (10) have the capacity to treat TB–HIV co-infected patients onsite, while two refer co-infected patients to another site. Four sites are able to treat these pediatric patients within the pediatric HIV clinic. Only one site reported the use of INH preventive therapy among TB-exposed pediatric HIV patients, even though this is recommended in the 2010 national guidelines. Of the sites that were able to provide site-level statistics on TB screening, an average of 86 percent of pediatric HIV patients were screened for TB upon enrollment into care from 2007 through 2010 (see Appendix A). It should be noted, however, that percentages ranged from 3 percent to 100 percent with a median of 14 percent. The figure of 86 percent is skewed by the largest site reporting 100 percent TB screening upon enrollment (see Appendix A).

Of particular provider concern was the difficulty in diagnosing TB in pediatric patients. Only one site reported the ability to process TB cultures on its premises. That site reported long turnaround times (i.e., several months) for receiving culture results, which are an impediment to timely treatment. Sites reported many other challenges in the treatment of TB–HIV co-infected patients. Pill burden was noted as a significant challenge. Respondents reported that it is difficult for children to take two daily regimens, and they have found that caregivers are sometimes opposed to this idea.

In addition to increased pill burden, patients and caregivers are often required to go to separate sites for TB and HIV follow-up and treatment, contributing to already substantial opportunity costs.[1] Providers also noted the need to alter ART regimens in TB–HIV co-infected children due to drug interactions.

Stockouts of TB drugs and a shortage of staff members trained in TB–HIV co-infection were other challenges mentioned by providers. In terms of successes, most sites with co-located TB and HIV clinics noted good communication between the two service providers. Providers were encouraged by the improved health of co-infected pediatric patients who adhere to both treatments. Sites also reported the ability to commence children on TB treatment immediately upon diagnosis, as long as adequate supervision is available.

SERVICE INTEGRATION

Service integration (defined as the provision of two or more services at the same time and at the same place) has been promoted as a strategy to improve access to care. The necessity for some people living with HIV to attend multiple facilities for various health care needs is often a barrier to optimal treatment outcomes. To assess service integration, sites were asked whether specific services were:

- Offered within the pediatric HIV clinic
- Offered onsite, but not within the pediatric HIV clinic
- Offered by referral only
- Not available onsite or by referral.

The number of sites offering services in each location category is displayed in Table 5. For those services accessed by referral to other sites, referral processes varied from formal to informal by site. There was no correlation between site type and the degree to which services had been integrated. Values over 50 percent are shaded in the table.

Sites reported that the majority of services are offered within the same facility, but not within the pediatric clinic or at the same time as the scheduled visit. Further investigation to systematically explore integration would need to be undertaken to explore the impact that integration may have on the quality of services received and overall outcomes of care.

SUPPORTIVE SERVICES

Children living with HIV and their caregivers can greatly benefit from comprehensive supportive services offered. All or nearly all sites reported the provision of disclosure support (17 sites), support groups (16 sites), family counseling (14 sites), and individual counseling (16 sites) under the umbrella of psychosocial services offered to pediatric patients and caregivers (see Table 6).

[1] An opportunity cost is the price of the next best thing you could have done if you had made a different choice. For example, although going to two separate sites to receive TB and HIV services may be the best choice for your health, this may require you to miss work, pay for childcare, and/or pay for transportation. These are the opportunity costs.

Table 5. Service Integration

Services	Number of Sites With:			
	Access Within Pediatric HIV Clinic	Access Onsite, but Not in Pediatric HIV Clinic	Access by Referral Offsite	No Access Onsite or by Referral
Antenatal care	1 (6%)	**13 (76%)**	3 (18%)	0 (0%)
Immunization (Expanded Programme on Immunization)*	2 (12%)	**12 (71%)**	3 (18%)	0 (0%)
Family planning	1 (6%)	**13 (76%)**	3 (18%)	0 (0%)
Integrated management of childhood illness, including malnutrition	3 (18%)	**13 (76%)**	1 (6%)	0 (0%)
Inpatient	3 (18%)	**10 (59%)**	4 (24%)	0 (0%)
HIV testing and counseling	8 (47%)	**9 (53%)**	0 (0%)	0 (0%)
ART adherence counseling	**16 (94%)**	1 (6%)	0 (0%)	0 (0%)
Phlebotomy	**11 (65%)**	6 (35%)	0 (0%)	0 (0%)
TB treatment	5 (29%)	**10 (59%)**	2 (12%)	0 (0%)
Psychosocial support	**12 (71%)**	5 (29%)	0 (0%)	0 (0%)
Linkages to other support services (i.e., housing, legal services)	5 (29%)	4 (24%)	5 (29%)	3 (18%)

Values over 50 percent are shaded.

* The total number of sites does not add up to 17 in this row due to two missing values.

Table 6. Psychosocial Support Services Offered by Site

Psychosocial Support Services	Number of Sites Offering Service
Disclosure support	17 (100%)
Support groups	16 (94%)
Family counseling	14 (82%)
Individual counseling	16 (94%)

GROWTH MONITORING

Nutrition and growth are crucial components of an HIV-positive child's overall well-being. All assessment sites reported that growth monitoring was done at each visit for pediatric HIV patients. Some sites performed this within the pharmacy because patients did not see a clinician at each visit. Children who were not growing at normal rates were provided with supplemental food if available and/or given micronutrients and other vitamins. Of the nine sites with site-level statistics on weight monitoring for 2007 through 2010, an average of 93 percent of patients had been weighed at their last visit. Similar to the site-level TB statistics reported previously, this percentage is skewed by the largest site reporting that 100 percent of patients were weighed at their last visit. The range of percentages reported by sites was from 45 percent to 100 percent with a median of 58 percent. The most popular method of growth monitoring was weight- and height-for-age charts, which were available at all sites (see Table 7). Zambia's under-five health cards contain a weight-for-age chart for weight monitoring. Eleven sites also used head circumference, 10 used dietary assessments, 9 used lab tests, and 7 used mid-upper arm circumference.

Table 7. Growth Monitoring Methods Used by Site

Growth Monitoring Methods	Number of Sites Using Method
Weight- and height-for-age charts	17 (100%)
Head circumference	11 (65%)
Mid-upper arm circumference	7 (41%)
Laboratory tests	9 (53%)
Dietary assessment	10 (59%)

FOOD SUPPORT, VITAMINS, AND MICRONUTRIENTS

Five of the 17 sites provide some sort of food support to pediatric HIV patients. This consists of Plumpy'Nut,[2] groundnuts, cooking oil, kapenta,[3] beans, and mealie-meal.[4] Most of these sites had experienced disruptions in their ability to provide this due to challenges such as Plumpy'Nut stockouts. Some sites had provided food support in the past through support from an external organization (e.g., the World Food Programme), however, had to stop once that support ended. Nearly all sites provide vitamins and/or micronutrients to pediatric HIV patients. Some sites prescribe these to every HIV-positive child, whereas others determine eligibility through clinical assessment.

COMMUNITY ENGAGEMENT

Many people living with HIV obtain support services within their communities. Linkages between HIV clinics and CBOs can help to bridge the gap between clinical care and psychosocial support. Twelve sites reported partnerships with CBOs linking pediatric HIV patients to community services. While the sites did not mention challenges specific to working with CBOs, many mentioned a lack of motivation from community health workers and speculated that it was rooted in the absence of compensation and the distances they were required to travel. Specific services provided by CBOs are discussed in the section on district community liaison interviews.

PHARMACY

Pharmacy functionality within facilities is central to meeting patients' needs. Nearly all site pharmacy personnel reported completing dispensing registers, using stock cards, maintaining cold chains, and ensuring security and quality assurance of pediatric HIV drugs. Twelve sites (71 percent) reported adequate storage, including refrigeration space, for stocks of pediatric HIV drugs. Only four sites reported having additional storage space available should the pediatric HIV program expand or if more drugs required refrigeration in the future.

With regard to maintaining drug stock, an average of nine days (median of one week) was needed to receive an order of pediatric HIV drugs from the time the order was placed. Although all sites reported a full stock of pediatric first-line regimens at the time of the assessment, 10 sites had

[2] Plumpy'Nut is a peanut-based paste with a nutritional value equal to F-100 of therapeutic milk. It is used to aid in the nutritional rehabilitation of children suffering from severe acute malnutrition.

[3] Fish similar to sardines.

[4] Coarse flour made from maize.

experienced stockouts of this regimen within the last quarter. Several sites mentioned the national NVP stockout in March 2011 and said that they managed it by decreasing the time between patient drug pickups (e.g., every two weeks instead of monthly). Fortunately, none of the assessment sites were ever completely stocked out of the drug during this period. Six sites reported that they do not routinely stock second-line pediatric regimens (including LPV/r). Most sites (13) required special approvals for second-line regimens or substitution pediatric ARVs. Four sites reported stockouts of CTX in the last quarter. Most sites (12) did not have fluconazole in suspension in stock for pediatric patients. With regard to PMTCT, four sites had run out of NVP suspension for infants within the last three months. There were no recently reported stockouts of pediatric phlebotomy supplies.

LABORATORY

Laboratories are another critical component of the comprehensive care provided to children with HIV. Dysfunction within a lab can have serious consequences, such as delayed treatment, for those in care. All assessment sites had onsite labs that were open Monday through Friday, with many open for part of Saturday as well. Three labs reported operating twenty-four hours per day, seven days per week.

According to laboratory personnel, DBS turnaround time averaged 18 days across sites (median = 14 days). The three polymerase chain reaction (PCR) processing labs reported a national stockout of processing kits lasting for several weeks within the last quarter (June through August 2011). All sites reported the ability to offer rapid testing without any supply stockouts. All sites were able to draw samples for CD4 testing and 13 were able to process samples onsite. Nearly half of these sites (seven) had experienced delays in processing CD4 samples in the last quarter due to reagent stockouts and/or equipment breakdowns. Sites that sent CD4 samples to an outside laboratory for processing reported turnaround times ranging from two days (two sites) to two weeks (one site).

Three sites reported the ability to process HIV-1 viral load tests within their own facility's laboratories, and one laboratory respondent noted that training and equipment for processing specimens for viral load would be available at the site in the coming months. Liver function testing was a challenge for sites. A quarter of the sites that could generally process liver function tests had experienced machine breakdowns and/or reagent stockouts in the last quarter. Sites that sent samples to outside laboratories reported that transport was an issue. Some sites that referred patients to outside laboratories reported that patients were charged a fee by the lab that was often prohibitive.

The laboratory challenge reported most frequently was insufficient man power. Laboratory staff are often overwhelmed by heavy workloads and more samples than they can manage. Dysfunctional laboratory machines are an issue for approximately one-third of sites (five). Some sites lack equipment to do necessary tests such as CD4 and full blood count, whereas others wait long periods of time for maintenance on frequently broken machines. Sites without well-functioning laboratories have challenges with transportation and receiving results. Several sites reported reagent stockouts, including those specifically for CD4 testing by flow cytometers. Finally, long turnaround times are a concern for both those laboratories collecting samples and those processing them.

WALK-THROUGH CHECKLIST RESULTS

BASIC RESOURCES

Data collectors observed the resources, tools, and layout of the 17 pediatric HIV clinics and asked staff members clarifying questions as needed. Table 8 shows the availability of basic resources among the sites. Thirteen sites had running water, although it was sometimes unreliable. Although all sites were wired for electricity, one was without electricity at the time of the assessment due to their prepaid system reaching its limit. Others reported frequent disruptions due to load shedding[5] in the region. Seven sites had clinic phones (i.e., mobile and/or landlines). The remainder used personal mobile phones or landlines located in another part of the facility.

Table 8. Basic Resources Available in HIV Clinics

Basic Resource	Number of Sites with Basic Resource
Running water	13 (76%)
Electricity	17 (100%)
Phone	7 (41%)

DECISION AIDS

Sites had a variety of pediatric HIV decision aids displayed throughout the clinics. All sites had a pediatric ART dosing chart, 16 had pediatric clinical staging charts, 15 had pediatric ART initiation and TB job aids, 14 had early infant diagnosis job aids, and 13 had job aids on pediatric ART adherence and pediatric treatment failure management. Eleven sites had pediatric nutrition decision aids and nine had job aids to assist with neurodevelopmental assessments.

SUPPLIES

Data collectors completed a checklist of whether specific supplies or equipment were available within the pediatric HIV clinic at each site. Results are presented in Table 9.

Table 9. Supplies/Equipment Available at Sites

Supplies/Equipment	Number of Sites with Supply/Equipment
Scales for infants	15 (88%)
Scales for older children	16 (94%)
Tape measures for head circumference	14 (82%)
Growth boards (for length/height)	14 (82%)
Growth charts	13 (76%)
Blood pressure cuffs in different sizes	5 (29%)
Oxygen saturation machine	5 (29%)
Stethoscope	17 (100%)

[5] Load shedding is when electric utility companies ration available electricity to their customers when the demand is greater than the supply. For example, some neighborhoods lose power every Tuesday and Thursday for several hours.

DISTRICT COMMUNITY LIAISON INTERVIEWS

District community liaisons oversee health-oriented CBOs within each DHMT. Data collection teams interviewed district community liaisons in seven of the nine districts visited. Interviews focused on CBOs providing support to HIV-infected children and their families and included topics such as referral systems, follow-up of patients, gaps in community services, and the potential for service expansion. Thematic analysis was used to interpret interview transcripts. A number of challenges to linking communities with health care facilities were highlighted.

Key Challenges According to District Community Liaisons:

- Few CBOs are actually dedicated to pediatric HIV patients
- Referral systems between CBOs and treatment facilities are week
- Lack of clear reporting structures.

The median number of CBOs supporting pediatric HIV initiatives in each district was one. The primary focus areas of these CBOs included assisting with referral to HIV testing (including early infant diagnosis), referral to treatment sites, adherence support, nutritional support, psychosocial support, tracking of defaulters, support for HIV-infected orphans and vulnerable children, and community sensitization. Financial support and support for HIV-positive adolescents were the areas addressed least by the CBOs.

WEAK REFERRAL SYSTEMS

A common theme that emerged from the interviews was the need for a uniform referral system between CBOs and treatment facilities. Although referrals do occur between these institutions, they were often described as "ad hoc." Inconsistent support was also discussed because most CBOs rely on donor funds, which are not consistently available.

THE NEED TO STRENGTHEN RELATIONSHIPS BETWEEN CBOS AND TREATMENT SITES

Interviews reflected that CBOs helped facility efforts to reduce attrition through patient outreach, including patient reminders for upcoming appointments and tracking patients with missed visits. They also engage mothers in pediatric HIV education. Respondents discussed the need to strengthen relationships between CBOs and treatment facilities through regular meetings, incentives (for volunteers and referrals), and updated trainings. They mentioned that HIV-infected children and caregivers would benefit from improvements in community education and sensitization (of children and orphans and vulnerable children), transportation assistance, and lay counselor trainings.

LACK OF CLEAR REPORTING STRUCTURES

Communication methods between CBOs and DHMTs varied by district. Some CBOs reported only to the treatment facilities they worked with, whereas others also reported to the DHMT. Some district community liaisons reported regular check-ins with CBOs and provided supportive supervision. The districts helped support CBOs with communication (between CBOs and facilities), referrals, supplies, incentives, and technical assistance. None of the district community liaisons were aware of new pediatric HIV-focused CBOs or the expansion of existing ones within their districts. Results suggest that strengthening referral systems and providing refresher courses could be areas of future focus within existing CBOs and DHMTs.

RECOMMENDATIONS

Although the challenges referenced in this report are not foreign to the MOH, implementing partners, or other pediatric HIV stakeholders, this assessment lends a voice to those on the frontlines of improving the lives of children living with HIV. Some recommendations follow that address the most common barriers to providing quality pediatric HIV treatment services which have been identified in this assessment.

TREATMENT

STAVUDINE (D4T)

Many sites continue to initiate pediatric ART patients on d4T. These sites may require MOH support in transitioning their standard first-line regimen to one with less toxicity, which is in line with national and WHO guidelines, as funding allows.

NEVIRAPINE (NVP)

Many sites require improved access to NVP alternatives for children who have been exposed to single-dose NVP.

TREATMENT FAILURE

Most sites reported few or no cases of treatment failure. Although this may be encouraging, it can also mean that treatment failure is not being identified. Until regular viral load testing becomes a reality, providers must do their best to identify these cases with the resources available to them and to act accordingly. Providers also need to be hypervigilant when it comes to immune reconstitution inflammatory syndrome, another life-threating concern for children on ART.

HUMAN RESOURCES

A system of improved accountability may make a small dent in the human resources issue. Several sites reported that the medical officer for their clinic had not appeared in months. Others reported providers who were on leave and sites had little or no information on their return. When data collectors mentioned one of these instances to a DHMT member overseeing personnel, he stated that he had not been aware that the clinician was away. This lack of communication and accountability seems to perpetuate the heavy workload on the hardest working staff members. To the contrary, data collectors also observed providers from clinics outside of the pediatric HIV clinic voluntarily lending a hand when they were able.

VOLUNTEERS

One strategy that has been utilized in the midst of human resources and funding limitations is using volunteers in roles such as adherence support workers. Although this is done out of necessity, volunteers—who are often people living with HIV themselves—take a great deal of pride in

supporting other people living with HIV. However, the lack of compensation is far from ideal. Where hourly wages are not feasible, efforts should be made to provide volunteers with the supplies they need to conduct their tasks and a transportation allowance.

CAREGIVERS

A key concern mentioned repeatedly by providers was caregiver neglect, especially for orphans. Although it is difficult to imagine an adult mismanaging a child's medication, it was reported often. Whether the neglect is intentional or not, it wreaks havoc on a child's physical and emotional well-being. These caregivers may be overwhelmed with providing and caring for other ill relatives and managing their own health issues while living in poverty. According to respondents, caregivers need guidance to bring children in for regular appointments instead of waiting until they are ill. Similar to the mentor mother model initiated by mothers2mothers, AIDSTAR-One suggests a mentor caregiver initiative whereby attentive (non-parental) caregivers mentor those who are struggling, through psychosocial support and advice.

DISCLOSURE

Beginning the disclosure process with an HIV-positive child is an overwhelming task for caregivers. Although there is increasing guidance on this issue from some of the leaders in HIV policy, such as the WHO, providers and caregivers carry this burden. One helpful resource for providers is included in the International Center for AIDS Care and Treatment Programs' *Adolescent HIV Care and Treatment: A Training Curriculum for Multidisciplinary Health Care Teams*, which was created specifically for Zambia. Module 7 is on "Providing Disclosure Counseling and Support." For disclosing to younger children, AIDSTAR-One is working with South to South and the François-Xavier Bagnoud Center to adapt three booklets to guide caregivers through the step-by-step disclosure process with HIV-positive children. AIDSTAR-One plans to offer these to USAID/Zambia for dissemination if deemed suitable by the MOH.

ADOLESCENTS

With the increasing population of ALHIV, more clinics should consider targeting services to this group. Non-adherence and other threats to good health can be exacerbated during this time of increased independence and free will. Several of the assessment sites did have targeted programs in place for ALHIV. AIDSTAR-One recommends information sharing between clinics with well-established ALHIV programs and those interested in starting one. In addition to the three disclosure booklets mentioned previously, AIDSTAR-One is working with Teen Club Botswana to adapt "Teen Talk," a comprehensive question and answer guide for ALHIV, for use among ALHIV in other countries. This is another document that will be offered to USAID/Zambia for dissemination. The guide was created hand-in-hand with ALHIV who participate in Teen Club Botswana, which is an impressive model aimed at empowering ALHIV that may be worth replicating in Zambia. Finally, AIDSTAR-One has created an Adolescent Toolkit and will be piloting it at sites in three countries, including Zambia, in the coming months.

LABORATORY

Providers rely on laboratory results to guide their treatment decisions. Laboratory personnel who took part in this assessment were typically overwhelmed with frequent equipment breakdowns and

an extensive number of samples to draw and/or process. One of the PCR labs, which should be among the most well-equipped labs in the country, reported the inability to process CD4 tests at the time of the assessment. There is a need for more laboratory technicians and technologists, and it may be worth offering incentives for entering this field if this is not already being done. A plan to diagnose the cause of machine breakdowns and reagent stockouts and to prevent their frequent occurrence are crucial steps in improving HIV treatment.

DATA

Through initiatives such as SmartCare and streamlined tools for data collection (e.g., registers), there have been advances in managing patient information. However, in order to improve the quality of care for pediatric HIV patients, there is a ways to go. Data systems and quality vary across implementing partners and sites. For those sites with inadequate systems, there is valuable time lost locating patient files, searching for missing information, and repeating services (e.g., laboratory tests) that have not been properly recorded. Patients suffer when providers are unable to make informed treatment decisions due to missing information. Similarly, when aggregate site-level data is inaccurate, program management and MOH officials are unable to identify important trends and areas for improvement. Continued technical assistance and capacity building in this area will serve to improve quality of care.

CONCLUSION

Although providers of HIV-positive children face numerous challenges, their eagerness to provide quality care to their patients was always apparent. Heavy patient loads, staff shortages, and inadequate resources (e.g., trainings, supplies, functioning equipment) often made the workload unmanageable; however, providers still mentioned with pride the improving health outcomes among their patients thanks to increased access to better treatment. Many of these providers recall when there were no treatment options for HIV-positive children. The change in prognosis for an HIV-positive child over the past decade is inspiring. Pediatric HIV treatment is a priority in Zambia and the country and has made impressive strides in reducing HIV-related morbidity and mortality among children. Zambia's response to children and adults living with HIV has many other high prevalence countries looking to them as a model. In spite of this, numerous challenges remain. Through continued problem identification and implementing prioritized recommendations such as those in the previous section, Zambia will help an increasing number of children living with HIV reach adolescence and adulthood.

REFERENCES

Joint United Nations Programme on HIV/AIDS (UNAIDS). 2009. "Zambia." Available at www.unaids.org/en/regionscountries/countries/zambia/ (accessed December 2011).

Joint United Nations Programme on HIV/AIDS (UNAIDS). 2010. *Global Report: UNAIDS Report on the Global AIDS Epidemic 2010*. Geneva: UNAIDS. Available at www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf (accessed September 2012).

Republic of Zambia Ministry of Mines and Mineral Development n.d. "Zambia: Investment Opportunities in the Mining Industry." Available at www.zambia-mining.com/country.html (accessed September 2012).

Republic of Zambia Ministry of Health (MOH). 2010. *Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia*, 2nd ed. Lusaka, Zambia: MOH.

United Nations Millennium Development Goals. n.d. "Goal 6: Combat HIV/AIDS, Malaria and Other Diseases." New York: United Nations. Available at www.un.org/millenniumgoals/aids.shtml (accessed December 2011).

World Health Organization (WHO). 2010. *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access: Recommendations for a Public Health Approach. 2010 Revision.* Geneva: WHO. Available at www.who.int/hiv/pub/paediatric/infants2010/en/index.html (accessed September 2012).

World Health Organization (WHO). 2011a. *Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access: Progress Report 2011*. Geneva: WHO. Available at www.who.int/hiv/pub/progress_report2011/en/ (accessed September 2012).

World Health Organization (WHO) 2011b. *Guideline on HIV Disclosure Counseling for Children up to 12 Years of Age.* Geneva: WHO. Available at http://whqlibdoc.who.int/publications/2011/9789241502863_eng.pdf (accessed September 2012).

RESOURCES

Botswana Teen Club: http://botswanateenclub.wordpress.com/tag/bipai/

International Center for AIDS Care and Treatment Programs (ICAP). Adolescent HIV Care and Treatment (Zambia): www.columbia-icap.org/resources/supporttools/index.html

mothers2mothers. Mentor Mother Model: www.m2m.org/what-we-do/mentor-mother-model.html

APPENDIX A: PROCESS DATA BY SITE FOR ENROLLMENT COHORTS (2007–2010)

	All (7–9) Sites with Data Provided		**Site 1**		**Site 2**		**Site 3**		**Site 4**		**Site 5**		**Site 6**		**Site 7**		**Site 8**		**Site 9**	
Variable (data for patients ≤ 15 years of age)	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Enrolled in HIV care	12,792		321	3%	837	7%	692	5%	72	1%	31	0%	218	2%	10,621	83%				
Initiated on ART	3,670		203	63%	524	63%	446	64%	36	50%	18	58%	129	59%	2,271	21%	10		33	
Initiated on ART within 4 weeks of eligibility	1,788	49%	103	51%	251	48%	205	46%	7	19%	15	83%	70	54%	1,113	49%	6	60%	18	55%
ART patients who were initiated on d4t	2,608	71%	159	78%	393	75%	273	61%	26	72%	16	89%	108	84%	1,596	70%	10	100%	27	82%
Patients who were screened for TB upon enrollment in HIV care	11,022	86%	46	14%	198	24%	41	6%	7	10%	1	3%	108	50%	10,621	100%				
Patients who ever received CTX (of those enrolled in HIV care)	4,082	32%	282	88%	640	77%	426	62%	61	85%	20	65%	83	38%	2,570	24%				

	All (7–9) Sites with Data Provided		Site 1		Site 2		Site 3		Site 4		Site 5		Site 6		Site 7		Site 8		Site 9	
Patients who ever received CTX (of those on ART)	1,192	85%	201	99%	467	89%	362	81%	36	100%	18	100%	79	61%			9	90%	20	61%
Patients weighed at their last visit (of those on ART)	11,915	93%	200	62%	494	59%	404	58%	34	47%	16	52%	126	58%	10,621	100%	5	50%	15	45%
ART patients who received adherence counseling at their last visit	3,256	89%	153	75%	307	59%	381	85%	23	64%	12	67%	105	81%	2,271	100%	1	10%	3	9%
Patients eligible for ART, of those enrolled	4,503	35%	251	78%	697	83%	497	72%	54	75%	18	58%	142	65%	2,844	27%				
Eligible patients who are on ART	3,425	76%	186	74%	465	67%	358	72%	32	59%	16	89%	97	68%	2,271	80%				
Patients on ART with evidence of treatment failure	177	5%	31	15%	84	16%	0	0%	0	0%	0	0%	0	0%	62	3%	0	0%	0	0%
Patients on second-line therapy following treatment failure	56	32%	7	23%	7	8%	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	42	68%	n/a	n/a	n/a	n/a

* Shaded cells indicate that data was unavailable.

APPENDIX B: OUTCOMES DATA FOR INITIATED PATIENTS BY SITE FOR ENROLLMENT COHORTS (2007–2010)

	All 9 Sites with Data Provided		Site 1		Site 2		Site 3		Site 4		Site 5		Site 6		Site 7		Site 8		Site 9	
Alive	2,715	74%	150	74%	329	63%	256	57%	31	86%	15	83%	81	63%	1,823	80%	9	90%	21	64%
Dead	171	5%	22	11%	38	7%	23	5%	0	0%	2	11%	17	13%	62	3%	0	0	7	21%
Lost to follow-up	516	14%	22	11%	122	23%	132	30%	4	11%	1	6%	23	18%	207	9%	0	0	5	15%
Transferred	268	7%	9	4%	35	7%	35	8%	1	3%	0	0%	8	6%	179	8%	1	10%	0	0%
Total	3,670	100%	203	100%	524	100%	446	100%	36	100%	18	100%	129	100%	2,271	100%	10	100%	33	100%

APPENDIX C: ASSOCIATIONS BETWEEN SITE CHARACTERISTICS AND PROCESS INDICATORS FOR ENROLLMENT COHORTS (2007–2010)

Logistic Regression Analyses of Process Variables by Selected Site Tool Variables (nine sites)

	Initiated ART (3,670 of 12,835)	**Screened for TB (11,022 of 12,835)***	**Screened for TB (401 of 2,214, UTH excluded)**	**Ever received CTX (4,111 of 12,835)**
Site Characteristic	***Odds ratio (95% confidence interval; p-value)***			
Rural vs. urban	3.53 (1.73, 7.22; 0.0005)	0.01 (0.001, 0.04; < 0.0001)	0.14 (0.02, 1.05; 0.06)	3.95 (1.89, 8.25; 0.0003)
Service integration score	0.73 (0.72, 0.75; < 0.0001)	4.251 (3.90, 4.62; < 0.0001)	2.18 (1.89, 2.52; < 0.0001)	0.72 (0.71, 0.73; < 0.0001)
Staff trained in pediatric HIV treatment vs. not	0.20 (0.18, 0.23; < 0.0001)	54.89 (46.95, 64.08; < 0.0001)	0.76 (0.61, 0.95; 0.02)	0.09 (0.08, 0.11; < 0.0001)
Staff retention problem vs. not	5.69 (5.12, 6.33; < 0.0001)	0.01 (0.008, 0.011; < 0.0001)	1.84 (1.35, 2.50; 0.0001)	5.32 (4.78, 5.92; < 0.0001)

Shaded cells indicate statistical significance at $p < 0.05$.

* Result driven by 100 percent TB screening at University Teaching Hospital (UTH; of 10,621 patients at that site).

APPENDIX D: ASSOCIATIONS BETWEEN SITE CHARACTERISTICS AND OUTCOME INDICATORS FOR ART PATIENTS (ENROLLMENT COHORTS 2007–2010)

Logistic Regression Analyses of Outcome Variables by Selected Site Tool Variables (seven sites)

	Dead vs. Alive (172 died of 2,887 total)
Site Characteristic	***Odds Ratio (95 percent confidence interval; p-value)***
Rural vs. urban	2.17 (0.49, 9.58; 0.31)
Service integration score	0.83 (0.78, 0.87; < 0.0001)
Staff trained in pediatric HIV treatment vs. not	0.42 (0.31, 0.59; < 0.0001)
Staff retention problem vs. not	2.57 (1.88, 3.51; < 0.0001)

Shaded cells indicate statistical significance at $p < 0.05$.

For more information, please visit aidstar-one.com.

AIDSTAR-One
John Snow, Inc.
1616 Fort Myer Drive, 16th Floor
Arlington, VA 22209 USA
Phone: 703-528-7474
Fax: 703-528-7480
Email: info@aidstar-one.com
Internet: aidstar-one.com