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TRANSITIONING CARE, SUPPORT, AND TREATMENT SERVICES FOR ADOLESCENTS LIVING WITH HIV

REGIONAL TECHNICAL CONSULTATION REPORT
FEBRUARY 7–10, 2012, GABORONE, BOTSWANA



AIDSTAR-One
AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES

AUGUST 2012

This publication was made possible through the support of 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 I and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

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AIDS Support and Technical Assistance Resources, Sector I, Task Order 1 (AIDSTAR-One) is funded by the U.S. Agency for International Development (USAID) under contract no. GHH-I-00-07-00059-00, funded January 31, 2008, through the support of USAID and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). 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 USG country teams in knowledge management, technical leadership, program sustainability, strategic planning, and program implementation support.

Recommended Citation

Bergmann, Heather, Malia Duffy, and Melissa Sharer. 2012. *Transitioning Care, Support, and Treatment Services for Adolescents Living with HIV: Regional Technical Consultation Report, February 7–10, 2012, Gaborone, Botswana*. Arlington, VA.: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.

Acknowledgments

Several individuals contributed to the development and administration of this field-driven learning consultation. AIDSTAR-One thanks the members of the U.S. President's Emergency Plan for AIDS Relief Prevention of Mother-to-Child Transmission/Pediatric Technical Working Group (TWG), USAID's Africa Bureau, and staff from USAID, the U.S. Centers for Disease Control and Prevention, and the U.S. State Department based in Botswana. In particular, AIDSTAR-One acknowledges Jenny Albertini from the USAID Africa Bureau; Anouk Amzel, Ryan Phelps, and Molly Rivadeneira from the PMTCT/Pediatric TWG; Bob Ferris and Tom Minior from the Adult Treatment TWG; and Elizabeth Berard and Rena Greifinger from USAID/Washington for their leadership and guidance. A special thanks to Ratanang Balisi, Joan LaRosa, and Mosarwa Segwabe from USAID/Botswana; Ambassador Michelle D. Gavin and Nkidi Moritshane from the U.S. State Department/Botswana; and Tim Hartmann from Peace Corps/Botswana for their invaluable support in-country. Many thanks to Betsie Frei and Amy Pepin for their support in making this technical consultation possible. Finally, AIDSTAR-One thanks all the presenters and participants—with special gratitude to the youth participants—for the experiences they shared and the contributions they made to the development and realization of the consultation. This report has been supported by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development under the terms of contract no. GHH-I-00-07-00059-00.

Cover photo from a presentation given at the conference, "Facility-based services for adolescents living with HIV" by Samson Lanje CDC-Botswana and B. Ryan Phelps USAID-Washington.

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ACRONYMS

ALHIV	adolescents living with HIV
ART	antiretroviral therapy
CDC	Centers for Disease Control and Prevention
CEYOHO	Centre for Youth of Hope
ICAP	International Center for AIDS Care and Treatment Programs
IMPACT	World Education Integrated Model for Pediatric AIDS Care and Treatment
M&E	monitoring and evaluation
PEPFAR	U.S. President’s Emergency Plan for AIDS Relief
PING	Positive Innovation for the Next Generation
PMTCT	prevention of mother-to-child transmission
SRH	sexual and reproductive health
SSI	Stepping Stones International
UNICEF	United Nations Children’s Fund
UNFPA	United Nations Population Fund
USAID	U.S. Agency for International Development
WHO	World Health Organization
ZPCT II	Public Sector HIV/AIDS Service Delivery Support Program in Zambia

INTRODUCTION

Advances in antiretroviral therapy (ART) and improved health services mean that increasing numbers of children infected with HIV perinatally will survive into adulthood. This group is emerging as a unique population that presents a special challenge to policymakers, programmers, and service providers, who need to understand this population's special needs in order to support their continued health and development.

In Gaborone, Botswana, from February 7 to 10, 2012, the Prevention of Mother-to-Child Transmission/Pediatric Technical Working Group (TWG) of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the Africa Bureau of the U.S. Agency for International Development (USAID), and AIDSTAR-One held a consultation to enable participants from eight countries (Botswana, Kenya, Mozambique, Namibia, South Africa, Uganda, Zambia, and Zimbabwe) to exchange knowledge and experiences in transitioning care, support, and treatment services for adolescents living with HIV (ALHIV). Participants were representatives of U.S. Government agencies (USAID, the Centers for Disease Control and Prevention, Peace Corps, and the State Department), PEPFAR implementing partners, ministries of health, and civil society organizations. Among the participants were young people (aged 15 to 24) from communities affected by HIV in Botswana, Kenya, Mozambique, Namibia, and Zambia.

Before the event, consultation facilitators and moderators hosted a special session to help youth participants prepare for their roles as co-facilitators and active participants in the technical consultation. After the gathering concluded on February 10, a smaller group convened to review the Transition Toolkit being developed by AIDSTAR-One for health and community care providers, families/caregivers, and adolescents. More information on this workshop can be found in Annex C and Annex D.

Transition can be both a mental and physical challenge for all ALHIV and, given the limited number of health providers throughout sub-Saharan Africa, it is likely that many adolescents will not physically transition to a new provider or to a new clinic. However, all adolescents will undergo a mental transition to adulthood that will require an increase in their ability to manage HIV. Although children perinatally infected may have very different clinical care needs than those behaviorally infected, social support services needs are similar. Practitioners, government officials, and program managers shared knowledge, experience, and resources as they discussed how best to care for ALHIV, and how to increase the services provided to adolescents infected perinatally and behaviorally. This consultation report is intended to reflect the discussions that took place over the three-and-a-half day consultation, and will complement the presentations, which can be found on the AIDSTAR-One website.

Related materials: www.aidstar-one.com/focus_areas/care_and_support/resources/technical_consultation_materials/adolescent_transition

WHY FOCUS ON ADOLESCENTS IN TRANSITION?

Adolescence is a challenging life stage for both youth and their caregivers. During adolescence, young people experience many social, emotional, and physical changes, and they become more responsible for their own health and well-being. Youth represent a significant proportion of the population in sub-Saharan Africa: of the over 840 million people in the region, half are under 18.

Youth are the future and are tied to a country's health and development. With 91 percent of the world's children living with HIV in sub-Saharan Africa, the need to focus on children and ALHIV is apparent, given the sheer number of young people and limited resources. Despite advances in prevention and treatment, HIV prevalence is still high, and multiple sectors must work together to address HIV issues.¹

"In our country, we have so many policies, we have policies for everything but we are failing in the implementation stage. We don't have programs that are very specific that tackle our challenges."

—Youth participant

The World Health Organization (WHO) defines adolescence as the period between 10 and 19 years of age. Many HIV programs are designed around the division between pediatric and adult care and treatment, without services specifically targeting adolescents. PEPFAR programmatic categories differentiate between pediatric and adult treatment, with adolescents falling into one category or the other without consistency in services or monitoring. Trained cadres of health or community care providers specializing in adolescent health, especially for

ALHIV, do not exist in most settings. Thus, the community and health service needs of ALHIV are often not being met.

Related presentations:

- [U.S. Government Perspective: Transitioning Care, Support, and Treatment Services for Adolescents Living with HIV](#)
- [Transitioning Care, Support, and Treatment Services for ALHIV: Evidence on Transition](#)

The evidence on ALHIV in sub-Saharan Africa is building, with many promising practices emerging at this consultation. Many adolescents perinatally infected with HIV are diagnosed late and do not learn of their HIV status until early adolescence, mainly due to gaps in counseling and testing services. Upon diagnosis, those infected perinatally start ART immediately, with adherence a top priority as they transition to self-management. ALHIV also have sexual and reproductive health (SRH) needs, which include accessing condoms, family planning, and PMTCT services. Little is known about how ALHIV experience grief and loss, but studies have shown that losing a mother to HIV is associated with poorer adherence to ART. Information is emerging on the neurocognitive and mental health issues of this population, but remains a gap in services.

In addition to the quantitative information from HIV surveillance and targeted studies, qualitative experiences from youth who have undergone or are in the process of transition from pediatric to adult care provide invaluable insight. Youth should be active participants in the discussion of transition services. Transition is not just a physical process focusing on the individual adolescent, but a dynamic process that should involve the adolescent, his or her health and community care providers, and his or her family and caregivers. The focus of transition should be self-management and should allow for the adolescent to make more decisions about his or her care in the clinical environment with support in the clinic, in the community, and at home. Young people need to know how to protect themselves and their partners from HIV infection and where to get services. Adolescent-sensitive services should treat young people with respect and make them feel comfortable.

"Africa's young populations will set the agenda for development by their sheer demographic might."

*—U.S. Ambassador to Botswana
Michelle D. Gavin*

¹ Population Reference Bureau. 2010. *Improving the Reproductive Health of Sub-Saharan Africa's Youth: A Route to Achieve the Millennium Development Goals*. Available at www.prb.org/pdf10/youthchartbook.pdf (accessed July 2012).

MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV/AIDS

Throughout this report, quotes from the youth participants reflect the real-life experiences behind the session topics discussed at the technical consultation. Their voices helped shape the discussions while giving personal examples of the issues. The consultation may provide an example of how to involve key populations in designing, planning for, and modifying services. Organizations and services targeting adolescents should involve them and provide them with the knowledge, skills, and opportunities to be active participants in programming. This is especially important for ALHIV, who are increasingly looking forward to healthy adult lives that are full of potential.

“As adolescents living with HIV, we don’t want to be part of the problem; we want to be part of the solution.”

–Youth participant

“People living with HIV and living in denial [should] see that there is no point in giving up on life, you can be whatever you want to be.”

–Youth participant

Meaningful Involvement of Youth

When the eight participating countries were assembling their delegations to attend the field-driven learning consultation, the consultation’s steering committee requested that one of the participants be a youth from a community affected by HIV. Of the 81 consultation participants, 11 were youth representing five countries: Botswana, Kenya, Mozambique, Namibia, and Zambia. The youth served as co-moderators on panel sessions, participated in small and country group work, gave presentations, and shared their experiences, ideas, and opinions throughout the week.

THREE COUNTRY EXAMPLES: BOTSWANA, KENYA, AND ZAMBIA

“Adolescents do not want to move to another clinic because we don’t feel comforted there.”

– Youth participant

The Baylor Children’s Clinical Centre of Excellence in Botswana, the Eastern Deanery AIDS Relief Program in Kenya, and the University Teaching Hospital Pediatric Centre of Excellence in Zambia provided examples of comprehensive transition programs. Some common lessons learned include the following components of promising transition practices:

- A multidisciplinary staff can help address the adolescent’s physical and social needs
- Beneficial disclosure, where the benefits of disclosure outweigh the risks, is encouraged so the adolescent may know his or her HIV status
- Social support services may be especially important to address self-stigma
- Working with communities to foster ownership of services can help move care out of the facility.

Challenges in transition are experienced by programs across the region. Decentralizing services from a large, well-equipped central hospital will require resources and training for staff. Adolescents may still be reluctant to transition to adult care, leaving the environment and providers they have become

accustomed to. Additional support is needed by adolescents to disclose their status to others, especially sexual partners. Despite outreach efforts, follow-up with adolescents may be difficult.

Related presentations:

- [Botswana: Baylor Children's Center of Excellence-A Comprehensive of Phased Approach to Transition](#)
- [Kenya: Eastern Deanery AIDS Relief Program](#)
- [Zambia: University Teaching Hospital Center of Excellence-Adolescents in Transition after South-to-South Visit](#)

FACILITY-BASED SERVICES

The International Center for AIDS Care and Treatment Programs (ICAP) in Kenya, the Empilweni Clinic at the Rahima Moosa Mother and Child Hospital in South Africa, and the Public Sector HIV/AIDS Service Delivery Support Program (ZPCT II) in Zambia have demonstrated holistic services for ALHIV in a facility setting. The three programs have addressed the changing needs of their adolescent populations, using clinic data to identify areas of strengths to build on and weaknesses to address.

Related presentations:

- [Kenya: ICAP, CHS, MMS—Minimum Package of Services for Adolescents](#)
- [South Africa: Empilweni Services—Clinic with Adolescent Treatment and Care Program](#)
- [Zambia: Prevention, Care, and Treatment Partnership—ZPCT II/FHI 360-HAART Scale-Up for Adolescents](#)

Baseline and routine assessments and regular data monitoring identify the specific services needed by and trends within the clinic population. As PMTCT programs continue to reduce perinatal transmission, the age of adolescent clients in HIV clinics will likely shift to be slightly older, with more adolescents infected behaviorally than perinatally. Analyzing clinic data as a team helps staff understand adolescents' needs and what those needs may mean for staff roles and responsibilities.

Moving forward, it might be beneficial to end the traditional clinical and programmatic separation between perinatally infected adolescents and behaviorally infected adolescents, and instead look at them as a group of young people with unique needs.

In addition to sensitizing staff to the needs of adolescents, peer educators and peer counselors can help make adolescents feel welcome at the facility. Having adolescents sit on advisory boards for programs and government relations, as they do at the Ariel Glaser Pediatric AIDS Healthcare Initiative in Mozambique and the Ministry of Health in Botswana, can provide adolescent input into how to design and offer youth-friendly services.

“These youth friendly services should include everything and be a package...[Starting with counseling and testing], it is best to finish everything in one facility.”

– Youth participant

In addition to establishing basic service packages for ALHIV, specific health and social needs arise during the time of transition. Instead of assuming their adolescent clients are not initiating relationships like their HIV-uninfected peers are, the multidisciplinary team of the Mildmay program

in Uganda addresses SRH needs through a variety of activities. Less well documented are the neurocognitive and mental health needs of adolescents transitioning in HIV care. The University of Botswana along with the University of Pennsylvania are beginning to look at neurobehavioral assessment and high-risk behaviors of ALHIV to help programs better address these issues.

Site Visit: Baylor Children’s Clinical Centre of Excellence

The Botswana-Baylor Children’s Clinical Centre of Excellence is an HIV clinic in partnership with Baylor College of Medicine and the Ministry of Health. Botswana-Baylor has the largest cohort of perinatal infected adolescents in Botswana; as of December 2011, over 80 percent of those aged 13 to 21 years were ready for enrollment into the transition program. As a result, Botswana-Baylor developed a transition program to prepare adolescents for adulthood. The Adolescent Transition Program includes a community clinic, psychosocial assessment and transition counseling, peer counseling and support, family and caregiver involvement through home visits, and group therapy and support, among other services.

Related presentations:

- [Uganda: Mildmay—Sexual and Reproductive Health and Prevention of Mother-to-Child Transmission](#)
- [Botswana: University of Botswana/University of Pennsylvania—Neurocognitive Aspects of HIV Among Adolescents](#)

“Children should be told their status earlier. The earlier the better. I knew my status earlier so that is why my CD4 never changed. I know what I’m doing and why I’m taking the medicine.”

– Youth participant

Sexual and reproductive health needs, especially around family planning, are common priorities to address at the health facility level. Adolescents need information on healthy relationships, communication with their (prospective) partners, and access to condoms. The emerging needs of adolescents center on psychosocial support, mental health, and substance use issues. However, it is important to remember that some challenging behavior is common—and even normal—among all adolescents, regardless of HIV status. Some programs have found integrating activities for both HIV-positive and HIV-negative adolescents have bolstered clinic attendance and helped to normalize services.

Common challenges include disclosure to the adolescents of their own status. Providers can help support caregivers in the disclosure process. Client follow-up is a challenge, and programs have different ways of addressing clients who do not return for care. Some programs use physical tracing to find the adolescents in the community and bring them back into clinical care. Again, many programs have faced the challenge of adolescents’ transitions from the pediatric to adult clinics because of their reluctance to leave the setting and staff who have provided familiar care for many years.

Continued success in PMTCT/prevention efforts is expected to lower the number of adolescents in need of transitioning services. Monitoring and evaluation can provide information to help direct resources to where they are most needed and to tailor them for the adolescent population. Options to increase sustainability of these services include

“I don’t have the same bond with the people at the adult center that I do at the pediatric center. They aren’t as welcoming. The biggest challenge is the type of bonding that will be there.”

– Youth participant

“It can be difficult to go from one group to another because I know the team and staff in the group I am in, and I feel comfortable there. I don’t feel like moving to an adult setting.”

– Youth participant

training of different cadres of health care workers to function as a team. Involving national AIDS strategies and government community mechanisms will also bolster sustainability after donor support phases out. Linking the services in the facilities to those in the communities may prove challenging because there are often not enough human or other resources to replicate facility-based models.

COMMUNITY, FAMILY, AND PERSONAL SERVICES

A successful transition from pediatric to adult care requires attention to the social support an adolescent receives beyond the facility into care provided at the community level and in the home. The World Education Integrated Model for Pediatric AIDS Care and Treatment (IMPACT) and Children First programs in Zimbabwe have supported nearly 2,000 children with holistic services, but those services require intensive monitoring and supervision, highlighting the need for serious commitment to supportive supervision in implementation. A strong example of providing social support to the caregivers as well as the children was shown by the South2South (S2S) Partnership in South Africa, which presented a strong example of providing social support to caregivers as well as children. The South2South Partnership has developed a disclosure booklet to provide guidance to the caregiver and child or adolescent.

Related presentations:

- [Zimbabwe: World Education IMPACT and Children First](#)
- [South Africa: South2South Partnership—Peer Support/Teen Club and Disclosure Booklet](#)

“My family should be a part of every step that I take. If I’m alone, it will be difficult for me to take the steps I should take. You are involving me but my dad is not here, and he may have a voice.”

– Youth participant

Supporting the adolescent in his or her social environment, which includes his or her family and community, can help to address some of the challenges of transition. A lack of transportation to clinic centers is a barrier for many adolescents. Decentralizing the services to the communities where they live may help increase access to services. Community-based activities may also address specific barriers: peer support can facilitate the disclosure process and community gardens can bolster the nutritional status of adolescents and their families. The IMPACT and Children First programs in Zimbabwe provide an example of how the time between diagnosis and ART initiation can be reduced by improving the availability of services in the lower level health facilities and local supply chain management.

Guidelines and tools to improve support services are useful but must include training and supervision. Follow-up training and ongoing supervision can ensure that tools are being used properly. Tools should be adapted for the local context and the local language.

Psychosocial support should be integrated into clinical care. Supporting both the adolescent and his or her family can boost clinical outcomes, improve treatment adherence, and get the adolescent started in needed services—such as ART—earlier. Adolescents who have graduated from pediatric to adult programs can serve as peer counselors in a clinic or community setting. Attending to the health of the caregiver may also be important because children with healthier caregivers have better outcomes themselves.

Existing programs provide examples of supporting the adolescent’s family unit. The Reach-Out Mbuya program in Uganda has holistic peer participation to support adolescents and their families in

their communities. The Positive Vibes program in Namibia provides treatment and social support, such as scheduling large meetings on holidays to avoid interfering with adolescents' school schedules. Working with families can reduce the burden on an adolescent before he or she is ready to take on the new responsibilities that accompany transition.

Site Visit: Centre for Youth of Hope (CEYOHO)

The Centre for Youth of Hope (CEYOHO) is a nongovernmental organization that was formed in 2001 by young PLHIV and formally registered in 2002. Its primary target group is young people living with HIV. CEYOHO provides care and support to young PLHIV and educates others on prevention and how to live positively with HIV. CEYOHO supports the development of income-generating activities by young people as a strategy to mitigate the socioeconomic impacts of HIV and AIDS. The organization is engaged in mobilizing communities and building awareness to promote community participation and involvement in such areas as PMTCT, voluntary counseling and testing, HIV prevention, and healthy life skills. CEYOHO implements activities to combat stigma and discrimination against PLHIV, provides education for young PLHIV and children affected by HIV, offers counseling and psychosocial services, conducts outreach in schools, and offers trainings and workshops.

Related presentations:

- [Uganda: Reach Out Mbuya—Holistic Peer Participation](#)
- [Namibia: Positive Vibes—Treatment and Social Support](#)

A comprehensive needs assessment conducted with the family can identify issues that affect the adolescent, caregiver(s), and other members of the household. Self-stigma may be a problem and could contribute to low self-esteem or other mental health issues.

Without adequate support, some adolescents may turn to transactional sex or sex work, putting them at risk for unintended pregnancies, sexually transmitted infections, and other negative health outcomes.

Again, performing a needs assessment in the family or community can help identify key protective factors that can minimize the risks adolescents face in their context.

In addition to working closely with families, programs can collaborate with schools to improve ART adherence and school attendance. Social workers can work with schools to support the disclosure process and to set up peer clubs in schools. Social workers and peer support programs can also operate in community centers and other areas to reach adolescents who are not in school. These school and community programs can target ALHIV and HIV-negative adolescents alike, possibly helping to reduce HIV-related stigma and to address common needs of all adolescents. Adolescents can be referred for other community- or facility-based services as needed.

“Parents should be involved because a young adolescent cannot take responsibility for everything.”

– Youth participant

“We used to have stigma and discrimination from society but there has been a shift. Now we, as individuals, self-inflict the stigma and discrimination. There should be comprehensive social support; it is not just about the support but about the quality.”

– Youth participant

MONITORING AND EVALUATION AND QUALITY IMPROVEMENT

Program examples highlight lessons learned in monitoring and evaluation (M&E), successful practices, and challenges. The IMPACT Program in Zimbabwe captures qualitative as well as quantitative information and maintains these data in a central database for monitoring. Recognizing that staff capacity is necessary for good systems, its staff receive training. However, staff turnover presents a challenge. The South2South Partnership focuses on clinics identified by the South African Department of Health as underperforming in ART. The program works to improve the quality of the data collected and reported by the clinics to accurately target interventions. The S2S Partnership also works to make the data valuable to the people who collect it. Reach-Out Mbuya in Uganda recognizes the need to include quality assurance in obtaining program goals to make sure clients are satisfied with services and return. However, given the divisions between departments within the organization, not all staff recognize the purpose of collecting data or how to properly document it, because that falls under the purview of the M&E department.

Programs share common M&E challenges. Adolescent-specific data may be difficult to extract, given the current indicators and age groups used. Medical records, ART cards, and reporting forms may not capture the whole story. Implementers, practitioners, and policymakers should review documentation to see if the information wanted and needed is being captured, and should revise forms as necessary. Donors should work together to align their reporting forms because there is often variation between indicators required by different donors. Moving to electronic systems is good for quickly integrating data from multiple sources, but they are not yet feasible in settings without access to a computer and the Internet.

Activities implemented by Positive Innovation for the Next Generation (PING) in Botswana provide examples of how technology can be incorporated into program monitoring and sustainability. Partnering with a national mobile phone provider, Mascom, PING sends text messages to enrolled participants to remind them to take their antiretroviral medication. The text messages have nothing to do with HIV; participants select from seven content areas, ranging from Bible quotes and inspirational messages to celebrity gossip. Participants are required to respond to each reminder message. The responses both provide participants with an opportunity to ask questions or raise concerns with program staff and serve as a built-in monitoring system. Donated by Mascom, a small amount of money is placed in the account of participants who respond to 90 percent of messages, suggesting a high adherence to ART. Not all adolescents have cell phones, so it is easier to reach adults, who are more likely to have them. Minors must bring a parent to enroll in the program, and PING conducts home visits to try to reach parents for enrollment, but some adolescents still miss the opportunity. Despite these challenges, PING provides a good example of incorporating technology into health programs to improve services and M&E.

Related presentation: [Botswana: Positive Innovation for the Next Generation-SMS and Measuring and Evaluation](#)

Site Visit: Stepping Stones International

Stepping Stones International is a nonprofit nongovernmental organization serving orphaned and vulnerable adolescents ages 12 to 18 and over, all of whom are either infected with or affected by HIV. Stepping Stones International has been operating an after school program for five years in Kgatleng District outside Gaborone, Botswana; in the past two years, Stepping Stones International has expanded some of its programs to five other districts. Stepping Stones International is based on a comprehensive, integrated model focusing on the individual, the individual's family, and the community within which he or she lives. The four core components of the program are life skills, psychosocial support, leadership skills, and advocacy/community mobilization. The program works with both HIV-positive and -negative youth to reduce stigma, and provides similar services to both groups. Stepping Stones International also considers the specific needs of the youth through outreach to families and by helping youth take their medications. The goal of the program is to ensure that youth gain the skills and confidence to proceed to employment, or vocational or tertiary institutions.

CURRENT RECOMMENDATIONS: UNICEF GUIDELINES

Recent technical consultations held by the United Nations Children's Fund (UNICEF), with WHO and the United Nations Population Fund (UNFPA), and upcoming UNICEF guidance documents provide recommendations for scaling up the response for ALHIV. Adequate care cannot be delivered by the health system alone. Other sectors, such as education, should collaborate to create sustainable systems that provide holistic care for adolescents. In order to design and deliver appropriate services, the number of ALHIV and where they live must be documented with monitoring tools, and the age groups currently in use should be revisited. Where surveillance sites and population-based surveys exist, adolescent age groups should be considered. With this information, programmers and policymakers can advocate for resources and prioritize this population.

Challenges at lower level facilities, such as their current capacity, have been documented, but the package of care necessary at these facilities needs to be defined. The minimum package of services should be realistic and should not create or rely on a vertical system, but should instead be integrated into existing systems. An assessment of existing services can identify services that overlap and opportunities to strengthen care for adolescents. Referrals for adolescents into an appropriate model of care also need to be improved.

Certain points on the care continuum could be strengthened. Diagnosis should be seen as an entry point to care, reinforcing the need to improve referrals from counseling and testing services. However, the age of consent for HIV testing and counseling may constitute another barrier for younger adolescents, so policies may need revising. Building the correct mix of post-test services can help adolescents get the services they want and need. Services for pregnant ALHIV should be incorporated into existing PMTCT services. Mental health issues, especially concerning bereavement and loss, warrant additional attention. All providers should receive training on what the potential issues are when an adolescent seeks care.

Efforts to lift stigma from counseling and testing services seem to be having their desired effects, but stigma still lingers in many settings and, in some places, may be getting worse. Stigma may have

"It's a flag that we talk about stigma but we don't program for it."

– Consultation participant

shifted to ART. There is still a need to address stigma around HIV in communities and in health facilities.

Possibly because they are a more familiar group, perinatally infected adolescents have been the focus of much of ALHIV service provision. However, the upper age range of adolescence reveals more and more behaviorally infected youth, especially young women. Among ALHIV between 10 and 14 years of age, there is roughly equal representation of girls and boys. However, among adolescents 15 to 19 years of age, young women out-represent young men. These behaviorally infected adolescents may be at increased risk for being lost to follow-up. Services should welcome adolescents regardless of the route of infection.

“Youth-friendly services are preferable, and there should be someone for follow-up. We also need to invest in intervention research. We focus on the what and we forget about the how.”

– Youth participant

Related presentation: [WHO/UNICEF/UNFPA Adolescent Guidelines: Community/Personal/Social/Facility](#)

NEXT STEPS

In addition to facilitating a south-to-south exchange of ideas and experience, a major outcome of the consultation was to identify next steps for participating countries to address transitional services for adolescents born with and living with HIV. Group work provided the opportunity for participants to synthesize information from the plenary sessions and make concrete plans to translate knowledge gained at the consultation into action.

Small groups of representatives from the different participating countries identified barriers and challenges in cross-cutting areas identified in this section. Key outcomes emerging from these small group meetings included identifying actions to address the barriers and gaps.

POLICY INTO PRACTICE

- Policies should support the availability of youth-friendly services in multiple settings; all clients—pediatric, adolescents, and adult—should be able to access services in one place.
- Services should begin with harmonization (i.e., improved coordination and integration) at lower levels.
- National policies should be developed and owned by the government and should involve adolescents in the process.
- Country-specific policies are varied, making regional analysis complicated.

CAPACITY DEVELOPMENT AND TRAINING INTO PRACTICE

- A first step toward building a cadre of peer leaders is to identify ALHIV who have successfully graduated from pediatric to adult care and provide them with skills and training.
- To help the adolescents feel as welcome in the adult clinic as they do in the pediatric clinic, providers in the adult clinic should be trained in interpersonal communication to help them be as warm and supportive as the pediatric clinic staff are.
- Training team members together can help facilitate task sharing and collaboration.

SERVICES AND PRACTICE

- Depending on the health facility level and resources, different levels of providers should be able to provide adolescent-friendly services, maximizing access.
- The quality of services in adult and pediatric clinics should be consistently high.

MONITORING AND EVALUATION AND QUALITY IMPROVEMENT

- Indicators should be disaggregated to include adolescent data.
- Any indicators, existing or new, should be linked to practice, and data collection should consider the capacity of the site; there is a need to connect the indicators to practice.
- In addition to developing data collection plans, the evaluation and dissemination component should be well-articulated so the stakeholders who need to see the data are able to do so.

SOCIAL MEDIA

- Social media is a channel for sharing information, and technologies are increasing the ability to do so, but the necessary technologies aren't available everywhere yet.
- Young people are using social media already, so health and social programs need to be proactive about using social media to reach young people with information and services.
- Other HIV services, such as counseling and testing, are already using social media to conduct outreach, and may have lessons to share with adolescent services.

Related presentation: [Small Group Work](#)

Participants also met in country teams to identify the steps they would take to address transition issues for ALHIV. Some of the next steps are listed as follows:

BOTSWANA

- Move toward models that address the needs of HIV-infected and HIV-affected young people to better address issues of stigma, HIV, and transition.
- Explore new ways of disseminating information using electronic communication such as Facebook and Twitter.
- Reach out to young people with disabilities.
- Develop M&E tools to enhance implementation.

KENYA

- Share information between partners working across the country.
- Improve the use of fixed-dose combinations to ease the transition from pediatric to adult ART.

MOZAMBIQUE

- Strengthen the role of the Ministry of Health in adolescent transition services and policies.

- Implement the approved integrated package of services for adolescents.

NAMIBIA

- Continue to implement the adolescent strategy, focusing on improving the community component and the role of community-based organizations and transitioning from donor funding.
- Integrate M&E into all systems.

ZAMBIA

- Create spaces for youth-friendly services.
- Harmonize pediatric and adult ART guidelines because both currently include recommendations for adolescents.

SOUTH AFRICA, UGANDA, AND ZIMBABWE (COMBINED COUNTRY GROUP)

- Develop a transition model to look at transition as a specific problem; use this focus on a specific problem and how to address it as a way to address adolescent issues in general.
- Improve access to and the use of data by programmers.
- Develop a task team to work specifically on transition within the working group on adolescents.

Related presentation: [Country Group Work](#)

CONCLUSION

Practitioners, programmers, and policymakers are learning more about ALHIV and their needs around transitioning from pediatric to adult treatment, care, and support services. Adolescents themselves should be included in the design, implementation, and evaluation of programs addressing transition. Advances in care and treatment are enabling children growing up with HIV to look forward to longer, healthier, more productive lives. Stakeholders must work together to help them realize that potential. Strengthening services for ALHIV can, in turn, strengthen health and social services for all adolescents.

“Adolescence is such a great stage in life. Living with HIV at this time is not an easy thing, so we have to make sure that they [adolescents living with HIV] will grow up to become whatever they want to become.”

– Youth participant

APPENDIX A: AGENDA

TRANSITIONING CARE, SUPPORT, AND TREATMENT SERVICES FOR ADOLESCENTS LIVING WITH HIV

FEBRUARY 7–10, 2012, GABORONE, BOTSWANA

MEETING OBJECTIVES

- Provide a forum for country programs to share promising practices that address challenges in designing, implementing, monitoring, and evaluating transitional services for adolescents born with and living with HIV.
- Identify 3 to 5 potential next steps for country programs to improve the quality of existing transitional services; these next steps may include proposals for implementation, further evaluation, south-to-south partnership/cross-learning technical assistance, or other next steps not yet identified.
- Explore methods of routine monitoring of transition services and policies and explore methods for evaluating these efforts.
- Present and finalize recommendations from the AIDSTAR-One technical brief on adolescents living with HIV.
- Present and finalize the AIDSTAR-One transition toolkit.

DAY I: TUESDAY, FEBRUARY 7, 2012

- 7:30–8:25 a.m. **Meeting Registration**
Pick up your name badge, meeting materials, and goodies at the registration table.
- 8:30–8:50 a.m. **Welcome**
Sara Bowsky (Master of Ceremonies) and Katlego Koboto (youth representative)
Brief Comments by Botswana U.S. Embassy U.S. Ambassador, Michelle D. Gavin
Opening Comments: Mr. Joseph Kefas, National AIDS Coordinating Agency (NACA) Coordinator-Botswana
Opening Comments: Katlego Koboto, Youth Peer Educator, Botswana-Baylor Children’s Clinical Centre of Excellence
- 8:50–9:05 a.m. **Meeting Overview**
Sara Bowsky and Katlego Koboto
- 9:05–10:05 a.m. **USG Perspective: Transitioning Care, Support, and Treatment Services for Adolescents Living with HIV**
Overview of the importance of transition and how PEPFAR is conceptualizing the issue. USAID/Africa Bureau and AIDSTAR-One will present the technical brief, Transitioning of Care and other services for

adolescent living with HIV in Sub-Saharan Africa, and the transition toolkit and checklist, the Toolkit for Transition of Care, and other services for adolescents living with HIV in Sub-Saharan Africa.

Presenters: Jenny Albertini and Melissa Sharer

Moderators: Sara Bowsky and Katlego Koboto

10:05–10:25 a.m.

Morning Break

10:25–11:25 a.m.

Youth Panel

Youth from Botswana, Kenya, Mozambique, Namibia, and Zambia will give an overview sharing their experiences and highlighting how stronger transitional services help support youth and why transitional care is critical.

Moderators: Ryan Phelps and Ratanang Balisi

11:25–12:25 p.m.

Three Country Examples on Transition

1. Botswana-Baylor Children’s Clinical Centre of Excellence: A Comprehensive of Phased Approach to Transition
Presenter: Marape Marape (Botswana)
2. Eastern Deanery AIDS Relief Program: Disclosure Facility Community Linkages
Presenter: Virginia Maina (Kenya)
3. University Teaching Hospital Center of Excellence: Adolescents in Transition after South2South Visit.
Presenter: Sylvia Mwanza (Zambia)

Moderators: Mosarwa Segwabe and Bolivia Jeremiah

12:25–1:25 p.m.

Lunch

1:25–2:25 p.m.

Facility-based Services for Adolescents Living with HIV

1. Technical Overview
Presenters: Ryan Phelps and Samson Lanje
2. ICAP, CHS, MMS Kenya: Minimum Package of Services for Adolescents
Presenter: Pauline Sisa (Kenya)
3. Empilweni Services: Clinic with an Adolescent Treatment and Care Program
Presenter: Karl Technau (South Africa)
4. Zambia Prevention, Care, and Treatment Partnership- ZPCT II/FHI 360: Highly Active Antiretroviral Treatment Scale-up for Adolescents
Presenter: Patrick Katayamoyo (Zambia)

Moderators: Bernadette Ng’eno and Nuria Mohamed

2:25–3:25 p.m.

Facility-based Services: Special Considerations

1. University of Botswana/University of Pennsylvania—Neurocognitive Aspects of HIV Among Adolescents
Presenter: Nthabiseng Phaladze (Botswana)

2. Mildmay: Sexual and Reproductive Health and PMTCT
Presenter: Esther Kawuma (Uganda)

Moderators: Emilia (Molly) Rivadeneira and Bolivia Jeremiah

3:25–3:45 p.m.

Afternoon Break

3:45–5:00 p.m.

Small Group Work

Participants will sign up for groups prior to arrival, at registration, or during the morning. Country teams will be strongly encouraged to make sure they have representation in each group. All groups will present back to the larger group.

Group A: Policy into Practice

Moderators: Elizabeth Berard and youth

Group B: Capacity Development/Training into Practice

Moderators: Sara Bowsky and youth

Group C: Services/Practice

Moderators: Ryan Phelps and youth

Group D: M&E and Quality Improvement

Moderators: Emilia (Molly) Rivadeneira, Bob Ferris, and youth

Group E: Social Media

Moderators: Anouk Amzel, Heather Bergmann, and youth

DAY 2: WEDNESDAY, FEBRUARY 8, 2012

8:30–8:45 a.m.

Preparing for Today

Review highlights from the previous day and review the agenda for the day.

8:45–9:45 a.m.

WHO/UNICEF/UNFPA Adolescent Guidelines: Community/Personal/Social/Facility

A presentation on implementation strategies being used that focus on both facility health services and community-based health/social services for adolescents living with HIV.

Presenters: Rick Olson and Susan Kasedde

Moderators: Sara Bowsky and Ueribinede Solaude

9:45–10:45 a.m.

Community/Family/Personal Services for Adolescents Living with HIV

1. Technical Overview

Presenters: Nkidi Moritshane

2. World Education IMPACT and Children First

Presenter: Alton Mpungu (Zimbabwe)

3. South2South Partnership: Peer Support/Teen Club and Disclosure Booklet

Presenter: Janine Clayton (South Africa)

Moderators: Jenny Albertini and Gorata Kgamanyane

- 10:45–11:00 a.m. **Morning Break**
- 11:00–12:30 p.m. **Small Group Work**
 Participants will sign up for groups prior to arrival, at registration, or during the morning. Country teams will be strongly encouraged to make sure they have representation in each group. All groups will present back to the larger group.
- Group A: Policy into Practice
 Moderators: Elizabeth Berard and youth
- Group B: Capacity Development/Training into Practice
 Moderators: Sara Bowsky and youth
- Group C: Services/Practice
 Moderators: Ryan Phelps and youth
- Group D: M&E and Quality Improvement
 Moderators: Emilia (Molly) Rivadeneira, Bob Ferris, and youth
- Group E: Social Media
 Moderators: Anouk Amzel, Heather Bergmann, and youth
- 12:30–1:30 p.m. **Lunch**
- 1:30–2:30 p.m. **Community-based Services: Special Considerations**
1. Reach Out Mbuya: Holistic Peer Participation
 Presenter: Richard Kilonzo (Uganda)
 2. Positive Vibes: Treatment and Social Support
 Presenter: Angelina Shetu (Namibia)
- Moderators: Mosarwa Segvabe and Mike Erasmus*
- 2:30–3:00 p.m. **Afternoon Break**
- 3:00–4:30 p.m. **Country Team Work**
 This is an opportunity for the country teams to come together and share information gathered regarding community, family, and personal services for adolescents living with HIV. Based on country context and the information presented during the day, teams will identify action items that can be undertaken to improve access to and utilization of transitional services. Teams will build on this work each day and make a presentation to the entire team at the end of day three.
- 4:30–5:00 p.m. **Presentation by Stepping Stones Youth Group**

DAY 3: THURSDAY, FEBRUARY 9, 2012

- 8:00–12:00 p.m. **Site Visits**
 Field site visits identified that show examples of programming for and with adolescents living with HIV.
Sites: Botswana-Baylor Children’s Clinical Centre of Excellence, Centre for Youth of Hope, Stepping Stones International, and Botswana Retired Nurses Society

- 12:15–1:15 p.m. **Lunch**
- 1:15–2:30 p.m. **Report Out from Site Visits**
Each site visit group will have the opportunity to provide a summary of the responses to key questions from the site visits, with a focus on implications for country action plans and next steps.
- 2:30–3:30 p.m. **Monitoring, Evaluating, and Quality Improvement Approach for Services for Adolescents Living with HIV**
1. Positive Innovation for the Next Generation: Short Message Services and M&E
Presenter: Ziada Tewelde and Katy Digovich (Botswana)
 2. Additional roundtable members:
 - a. Janine Clayton (South Africa)
 - b. Richard Kilonzo (Uganda)
 - c. Alton Mpungu (Zimbabwe)
- Moderators: Allison Russell and Susan Kasedde*
- 3:30–3:45 p.m. **Afternoon Break**
- 3:45–5:00 p.m. **Open Spaces**
Open Spaces is a time for spontaneous networking and meeting with your colleagues over topics of common interest. There will be some prereserved topic tables, and many open ones. Please don't miss this chance for a productive discussion!

DAY 4: FRIDAY, FEBRUARY 10, 2012

- 8:30–8:45 a.m. **Welcome to the Last Day**
- 8:45–9:30 a.m. **Sharing of Information from the Small Working Group**
Each group will present on key issues, challenges, and solutions discussed.
Moderator: Elizabeth Berard
- 9:30–11:30 a.m. **Country Action Plans: Bringing It All Together and Next Steps (Includes rolling Morning Break)**
After the site visit the groups will reconvene in small country-based groups to consider the following questions: 1) potential for replication in their country, 2) key adaptations to consider in replication, 3) what resources would be needed to make those adaptations, and 4) what policy changes need to take place to support these efforts. Based on country context and the information presented during the first three days, teams will identify action items that can be undertaken to improve access to and utilization of services by adolescents and their family/caregiver(s). Country teams will identify major activities, stakeholders that need to be involved, and any technical assistance needs that have to be addressed in order to achieve results. During this time, teams will review the country team work done on the previous days to identify opportunities for technical assistance and to ensure seamless access to services over these time periods.

11:30–12:30 p.m.

Country Presentations and Closing Plenary Session

Country groups will present on successes, missed opportunities and gaps identified, and possible program solutions to address them, with a focus on the services that will ensure that clients are served through a continuum of response.

Moderators: Jenny Albertini, Sara Bowsky, and Katlego Koboto

12:30–1:30 p.m.

Lunch

OPTIONAL: Half day (LIMIT: 20 person capacity)

1:30–4:30 p.m.

Transition Toolkit Feedback Session

AIDSTAR-One is pleased to invite you to a workshop for the Toolkit for Care of Other Services for Adolescents Living with HIV. AIDSTAR-One will model a brief toolkit training session that includes program prioritization, case study analysis and response, and also allow for a process of face and content validation of the toolkit among key participants at the workshop. Participant feedback will be utilized to adapt the toolkit prior to the official pilot. The workshop will be located at the conference facility and will take place on the last day of the conference.

Moderator: AIDSTAR-One

APPENDIX B: REGIONAL TECHNICAL CONSULTATION PARTICIPANT LIST

Name	Country	Organization
Nidia Abdulla	Mozambique	Ministry of Health
Jennifer Albertini	USA	U.S. Agency for International Development (USAID)
Anouk Amzel	USA	USAID
Ratanang Balisi	Botswana	USAID
William Bapati	Botswana	University Research Co. (URC)
Tummie Basha	Botswana	Centre for Youth of Hope (CEYOHO)
Kesego Basha-Mupeli	Botswana	CEYOHO
Elizabeth Berard	USA	USAID
Heather Bergmann	USA	John Snow, Inc. (JSI)
Sara Bowsky	Mozambique	USAID
Mwenya Chiti	Zambia	Youth delegate
Janine Clayton	South Africa	Stellenbosch University
Katy Digovich	Botswana	Positive Innovation for the Next Generation (PING)
Malia Duffy	USA	JSI
Mike Erasmus	Botswana	Inner Self-Confidence
Joaquim Fernando	Mozambique	FHI 360
Bob Ferris	USA	USAID
Michelle Gavin	Botswana	U.S. Embassy
Rukaiyah Ginwalla	Zambia	Centers for Disease Control and Prevention (CDC)
Rena Greifinger	USA	USAID
Tim Hartman	Botswana	Peace Corps
Ochiawunma Ibe	Namibia	USAID
Rosalia Indongo	Namibia	USAID
Bolivia Jeremiah	Botswana	Botswana Family Welfare Association (BOFWA), youth delegate
Haruna Jibril	Botswana	Ministry of Health
William Jimbo	Botswana	CDC
Kebba Jobarteh	Mozambique	CDC
Sylvia Mwanza Kabaghe	Zambia	University Teaching Hospital (UTH) Adolescent Coordinator
Anne Kagema	Kenya	EDARP
Susan Kasedde	USA	UNICEF
Patrick Katayamoyo	Zambia	Public Sector HIV/AIDS Service Delivery Support Program in Zambia (ZPCT II)
Febby Banda Kawamya	Zambia	Pediatric Centre Of Excellence
Bedoki Kayawe	Botswana	Muegi

Name	Country	Organization
Joseph Kefas	Botswana	National AIDS Coordinating Agency (NACA)
Gorata Kgamanyane	Botswana	Stepping Stones International, youth delegate
Richard Kilonzo	Uganda	Reach Out Mbuya HIV/AIDS
Katlego Koboto	Botswana	Botswana-Baylor Children's Clinical Centre of Excellence, youth delegate
Joan LaRosa	Botswana	USAID
Eda Lifuka	Zambia	Department of Defense
Esther Machakaire	Botswana	CDC
Lebo Madisha	South Africa	National Department of Health
Virginia Maina	Kenya	Eastern Deanery AIDS Relief Program (EDARP)
Joy Manengu	Zambia	USAID
Marape Marape	Botswana	Botswana-Baylor Children's Clinical Centre of Excellence
Richard Matlhare	Botswana	National AIDS Coordinating Agency
Idah Mendai	Namibia	Ministry Of Health and Social Services
Mathe Mmegi	Botswana	Newspaper
Tish Mobley	Botswana	Stepping Stones International
Queen Moeletsi	Botswana	Botswana Retired Nurses Society (BORNUS)
Nuria Mohamed	Kenya	EDARP
Rosemary Mokgosi	Botswana	Peace Corps
Kelennetse Moleta	Botswana	Ministry of Youth Sports and Culture
Iris Molokwane	Botswana	State Department
Nkidi Moritshane	Botswana	CDC
Alton Mpungu	Zimbabwe	World Education
Anne Mwangi	Kenya	National AIDS & STI Control Programme (NASCOP)/Ministry of Health
Barbara Namata-Mukasa	Uganda	Mildmay Uganda
Hemlaxmi Natalal	Mozambique	FHI360
Marytha Neo	Namibia	Ministry Of Health and Social Services
Bernadette Ng'eno	Kenya	CDC
Kebabonye Nthobatsang	Botswana	Ministry of Local Government
Rick Olson	South Africa	United Nations Children's Fund (UNICEF)
Greg Pachuta	USA	Peace Corps
Lila Pavey	Botswana	Stepping Stones International
Nthabi Phaladze	Botswana	Ministry Of Health and Social Services
B. Ryan Phelps	USA	USAID
Gosata Rabantheng	Botswana	Ministry of Health
Luccyn Raditladi	Botswana	CEYOHO
Irene Ramatala	Botswana	USAID
Januario Reis	Mozambique	USAID
Emilia Rivadeneira	USA	CDC

Name	Country	Organization
Allison Russell	South Africa	Regional HIV/AIDS Program USAID
Laona Segaetsho	Botswana	U.S. Embassy
Mosarwa Segwabe	Botswana	USAID
Refilwe Sello	Botswana	Botswana-Baylor Children's Clinical Centre of Excellence
Melissa Sharer	USA	JSI
Angelina Shetu	Namibia	Youth delegate
Pauline Nanjowe Sisa-Kiptoo	Kenya	International Center for AIDS Care and Treatment Programs (ICAP)
Uerihuede Solaude	Mozambique	Youth delegate
Karl Technau	South Africa	Empilweni Services and Research Unit (ESRU)
Ziada Tewelde	Botswana	PING
Paula Vaz	Mozambique	Ariel Glaser Pediatric AIDS Foundation

APPENDIX C: TRANSITION TOOLKIT WORKSHOP SUMMARY

After the conclusion of the technical consultation, 24 participants, including 2 youth participants, took part in a workshop to review the transition toolkit being developed by AIDSTAR-One. Using a case study approach, the workshop participants applied the toolkit, identifying the sections and tools relevant to the case, and prioritizing their application based on need and (theoretically) available resources. Participants provided oral and written feedback that was subsequently used to revise the toolkit and also in the training materials, which were partially used at the workshop.

AGENDA

- 1:30–2:30 p.m. **Introduction to the Transition Toolkit**
The transition toolkit will be presented. This session will include general information on the transition toolkit including an introduction to the contents, requirements prior to use, how it is organized, and how it should be utilized.
Moderator: Malia Duffy, AIDSTAR-One
- 2:30–3:30 p.m. **Utilization of the Case Study Approach for the Transition Toolkit**
In small groups, participants will utilize case studies to decide how they will utilize the transition toolkit to provide care for the adolescent and his or her family/caregiver(s). Participants will share their findings with the larger group.
Moderator: Heather Bergmann, AIDSTAR-One
- 3:30–4:30 p.m. **Feedback on the Transition Toolkit and Case Studies**
Participants will be given the opportunity to review the transition toolkit and case studies and will provide oral and written feedback to the moderators.
Moderator: Melissa Sharer, AIDSTAR-One

APPENDIX D: TRANSITION TOOLKIT WORKSHOP PARTICIPANT LIST

Name	Organization
Nidia Abdula	Ministry of Health/Mozambique
William Bapati	University Research Company/Botswana
Elizabeth Berard	U.S. Agency for International Development (USAID)/Washington
Sara Bowsky	USAID/Mozambique
Janine Clayton	South2South Partnership/South Africa, University of Stellenbosch
Joaquim Fernando	FHI 360/Mozambique
Rena Greifinger	USAID/Washington
Ochi Ibe	USAID/Namibia
Rosalia Indongo	USAID/Namibia
Susan Kasedde	UNICEF
Patrick Katayamoyo	Public Sector HIV/AIDS Service Delivery Support Program in Zambia (ZPCT II)/Zambia
Febby Banda Kawamya	Pediatric Center of Excellence/Zambia
Richard Kilonzo	Reach Out Mbuya/Uganda
Pauline Sisa Kiptoo	International Center for AIDS Care and Treatment Programs/Kenya
Katlego Koboto	Botswana-Baylor Children's Clinical Centre of Excellence, youth delegate
Idah Mendai	Ministry of Health and Social Services/Namibia
Queen Moeletsi	Centers for Disease Control and Prevention/Kenya
Hemlaxmi Natalal	Stepping Stones International/Botswana
Marytha Neo	Ministry of Health and Social Services/Namibia
Bernadette Ng'eno	Centers for Disease Control and Prevention/Kenya
Lila Pavey	Stepping Stones International/Botswana
Irene Ramatala	USAID/Botswana
Januario Reis	USAID/Mozambique
Emilia (Molly) Rivadeneira	Centers for Disease Control and Prevention/Atlanta

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