TRANSITIONING OF CARE AND OTHER SERVICES FOR ADOLESCENTS LIVING WITH HIV IN SUB-SAHARAN AFRICA

TECHNICAL BRIEF

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INTRODUCTION

Sub-Saharan Africa has the highest HIV burden in the world, with 67 percent of the estimated 34 million people living with HIV. Globally, children under 15 years are particularly hard hit: 3.4 million are living with HIV, 90 percent of whom live in sub-Saharan Africa (WHO 2011a).

Approximately one-third of infants born to mothers living with HIV are not on antiretroviral therapy (ART), either for their own clinical care or for the prevention of mother-to-child transmission, and will be infected during pregnancy, birth, or breastfeeding. Until recently, it was assumed few children infected during this period would live beyond their fifth birthday. Recent data has emerged to challenge this assumption because children infected via vertical routes are now entering adolescence in sub-Saharan Africa. Recent projections suggest that 36 percent are slow progressors and have a median survival age of 16 even without access to treatment (Ferrand et al. 2009a). Moreover, many children who acquire HIV during the perinatal period and are subsequently on ART are now expected to live a long healthy life. However, they live with a host of clinical and psychosocial care needs that most community support and health systems in sub-Saharan Africa are not equipped to address (Ferrand et al. 2010; Li et al. 2010; Petersen et al. 2010; Valenzuela et al. 2009). With recent evidence showing that ART can prevent sexual HIV transmission among serodiscordant couples (Cohen et al. 2011), decisions about when to start treatment, adherence, and retention become even more critical to address among adolescents living with HIV. Transition can be both a mental and physical reality for all adolescents living with HIV, and services should promote self-care that includes adherence to ART and the adoption of appropriate individualized prevention strategies to help reduce further HIV transmission (The Lancet 2011a).

Evidence shows that poorly planned transitions can result in harmful consequences such as treatment nonadherence and loss to follow-up in care and support services, both severely impacting the health of the adolescent and having social and educational repercussions (Ferrand et al. 2010; Gilliam et al. 2010; Machado, Succi, and Turato 2010). With 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 are going through a mental transition to adulthood. Although children perinatally infected may have very different clinical care needs, those adolescents infected via behavioral routes need similar support services. This technical brief therefore provides guidance for all adolescents living with HIV, and can be adapted for a variety of health care settings.

POPULATION OF CONCERN

As vertically infected adolescents (aged 10 to 19 years) emerge as a unique and unplanned for population, people living with HIV, policymakers, programmers, and service providers must focus attention and develop a stronger understanding of their unique health and social support needs, which many times mirror the needs of adolescents infected via behavioral routes. Table 1 shows vertically infected adolescents are more likely to be in advanced stages of HIV, with a history of opportunistic infections, more complicated comorbidities, different mental health support needs, and more resistant mutations that require complex treatment regimens than adolescents infected via behavioral routes (Gipson and Garcia 2009; Prendergast et al. 2007; Ross et al. 2010; Vijayan et al. 2009). Because many vertically and behaviorally infected adolescents do not know their HIV status, a key service gap is the lack of appropri-

ate counseling and testing services available for this population in both rural and urban settings (Coovadia and Mantell 2010; Ferrand et al. 2010). This can pose significant barriers to a successful transition into adult or adolescent-friendly HIV care.

Adolescents infected perinatally and behaviorally have different clinical needs, as exhibited in Table 1; however, all adolescents need certain care and support services, as exhibited in Table 2. For those perinatally infected, important care and support differences include specific psychosocial, disclosure, and stigma issues that are related to the fact that they acquired their infection from a parent.

As the number of adolescents living with HIV (ALHIV) continues to grow, the need to improve services, policies, and programs intensifies. This technical brief provides guidance for program managers and policymakers in order to develop services for ALHIV and their families/caregivers as they transition toward HIV self-management and adult clinical care. Focusing more specifically on the transitional needs of adolescents vertically infected with HIV, the contents have relevance for those adolescents infected via behavioral routes, as highlighted by Table 2. Providing a framework for transition, this brief outlines essential care, support, and treatment services to best meet the multiple unique needs of ALHIV. This technical brief also offers promising approaches and outlines a model of adolescent transition of HIV care and other services. Highlighting key principles and recommendations, this brief offers guidance to countries and programs on how to provide the multidisciplinary care, support, and treatment services these adolescents need and deserve.

TABLE 1. DIFFERENCES BETWEEN ADOLESCENTS BY TRANSMISSION ROUTES	
Perinatally infected	**Behaviorally infected**
More likely to be in advanced stages of HIV	Earlier stages of HIV
More likely to have opportunistic infections	Fewer opportunistic infections
More likely to not be on first-line drugs and in need of complex ART regimens	Less likely to need ART and resistance to ART less likely
More obstacles to achieving self-management and autonomy	Less likely to experience obstacles to achieving self-management and autonomy
More physical and developmental delays	Less likely to have physical and developmental delays
Higher risks of complications during pregnancy	Lower number of complications during pregnancy
Higher mortality rates	Long-term chronic disease outlook
May not know HIV status although may have been in treatment	May experience more adherence challenges
More likely to have experienced multiples losses related to HIV (parents, siblings, etc.)	More likely to have denial and fear of HIV
More secrecy regarding disclosure	More likely to be misinformed about HIV
Struggling with issues related to engaging in intimacy, sexuality, and sexual identity	May distrust clinical facilities
May have heightened concerns about pregnancy and starting families	Lack of belief in clinical treatment to prevent vertical HIV transmission
More likely to have support from family/caregiver and health provider	More likely to lack familial, clinical, and social supports

Source: Gibson and Garcia 2009; HIV Transitional Care Working Group 2011.

TABLE 2. NEEDS OF ADOLESCENTS

Care and support needs	Perinatally infected	Behaviorally infected	HIV-negative adolescents
Access to HIV testing and counseling	All	All	All
Access to sexual and reproductive health services	All	All	All
Disclosure (self & others)	All	All	None
Psychosocial support	All	All	All
Stigma (self & others)	All	All	Some
HIV prevention	All	All	All
Access to HIV care	All	Some	Some
Access to prevention of mother-to-child transmission services	All	All	All
Access to ART	All	Some	None
Adherence	All	Some	None
Transition of HIV care	All	All	None

Source: Olson and Kasedde 2012.

DEFINITION OF TRANSITION

Transitioning HIV care and other services (hereinafter referred to as "transition") is only one of many transitions adolescents face. Adolescence is a developmental phase between childhood (under 10 years) and adulthood (over 19 years) characterized by physical, psychological, and social changes at the individual level (WHO 2010). Within this timeframe, there is a wide range of developmental stages, with many programs separating the two groups into early adolescence (10 to 14 years) and late adolescence (15 to 19 years). Although 18 is the legal age of adulthood in many countries in sub-Saharan Africa, adult behaviors are not necessarily fully adopted by then. Therefore, many countries continue to provide "youth" health and social support programs for people well into their 20s.

Transition for adolescents with special health needs, such as HIV, has been described as "a multifaceted, active process that attends to the medical, psychological, and educational or vocational needs of adolescents as they move from the child focused to the adult focused health care" (Reiss and Gibson 2002, 1309). Usually starting with a partial disclosure to the child, the physical act of transitioning to adult HIV care is a long-term process, and is not bound to a particular age. The transition must be based on developmental readiness, maturity, and responsibility (Ferrand et al. 2010; Gilliam et al. 2010). Transition can correspond with a time when self-exploration and risk-taking behaviors are common. Therefore, services must address complex issues such as sexual debut, adolescent pregnancy, short-term consecutive partners, and experimentation with alcohol and drugs (Machado, Succi, and Turato 2010; Ross et al. 2010; WHO 2010). With foresight and proper planning, transitional services can maximize resiliency, minimize risk factors, and promote personal growth. Transition is hopeful; it is an opportunity to increase adolescents' autonomy and their connectivity within the community (Gilliam et al. 2010; Gipson and Garcia 2009).

For many ALHIV, transition begins with learning they are positive, either through disclosure or testing. In many situations, adolescents have been in clinical

care, taking ART without explicitly knowing their status. For others, an HIV diagnosis often occurs only after several years of poor health, typified by chronic health complications and no or limited use of health services (Andrews, Skinner, and Zuma 2006; Ferrand et al. 2009a; Prendergast et al. 2007). Transition programs must be tailored to a patient's individual capacities, readiness, and developmental age. A "one-size-fits-all" approach will not work. For ALHIV who have known their status since they were infants or young children, their pediatric health care provider and caregiver should be active participants in the transition process. In many settings, the pediatric and adult care provider are the same person, so having a strong understanding of the unique needs of adolescents is important for providing appropriate care.

To be successful, the transition process must be smooth and planned in advance. Services that remain uninterrupted produce more optimal health outcomes. Planning for transition, and transition itself, requires flexibility and high levels of interaction and communication among adolescents, service providers, and their family members/caregivers. Special consideration should be made for ALHIV in rural areas, who are more isolated and have intermittent services (Ferrand et al. 2010; Hodgson et al. 2011), creating even more barriers for the transition process.

TRANSITION: IDENTIFY ADOLESCENT NEEDS

Transitioning adolescents into adult HIV care is not a simple process; both individuals and systems need to be adaptable. Time- and labor-intensive, the physical act of transition is only one of many transitions an adolescent undergoes. With clear planning and forethought, the process can create a sense of partnership between the adolescent, family members, and health providers, and lead to stronger management

of HIV over time. Programs that operate from a strengths perspective can build individual and family capacities, competencies, possibilities, visions, and hopes (Saleebey 1996). This perspective acknowledges and strengthens individual and familial protective traits and does not ignore or downplay real problems. Providing an opportunity for ALHIV to build upon their talents operating from a strengths perspective allows the adolescent to learn from missteps and to minimize harmful behaviors. Regardless of how the adolescent learns of his or her HIV status, initial transition efforts need to address the challenges of this period, building on individual, family, and community strengths. It is from this initial point that transition policies and programs must understand and respond to adolescent's special needs while also building resiliency factors and coping mechanisms.

UNIQUE NEEDS OF ADOLESCENTS LIVING WITH HIV

The journey into adulthood, whether it involves living with HIV or not, is a period where an individual undergoes major social, physical, and psychological changes. This transition can be more difficult for ALHIV that face additional challenges due to the loss of parents and other relatives (Andrews, Skinner, and Zuma 2006; Cluver, Gardner, and Operario 2007; Petersen et al. 2010), a delayed onset of puberty (Li et al. 2010), and difficulty coping with adherence, disclosure, stigma, and sexual relationships (Menon et al. 2007; Miles, Edwards, and Clapson 2004; Ross et al. 2010; While et al. 2004; WHO 2009). It is important that transition programs and policies recognize and adapt to these needs, while also taking into consideration the developmental process of adolescence.

Stigma is one of the most difficult issues to address with an HIV diagnosis, regardless of how old people are when they find out about their status. With regard to ALHIV, stigma overlays the entire transition

process. Even with treatment advances and increased public awareness of HIV, stigma has been shown to greatly impact adherence, disclosure, and functioning of providers and ALHIV (Brown, Lourie, and Pao 2000; Earls, Raviola, and Carlson 2008; Fielden et al. 2006; Strydom and Raath 2005). Stigma impacts the decision to disclose HIV status, and is a key reason why many ALHIV experience delays in the full disclosure of their diagnosis from their family/caregiver or health care provider (WHO 2011b). Contending with stigma and the psychological, physical, and social changes associated with puberty and adolescence make stigma particularly important to address during the process of transition (Howell and Hamblin 2011). The cultural context, beliefs, and barriers related to stigma and living with HIV are widely different throughout sub-Saharan Africa, and they must be identified and addressed to improve services when working with ALHIV (Brown, Lourie, and Pao 2000; Doku 2010; Prendergast et al. 2007; Punpanich et al. 2008; Vaz et al. 2010; Wouters, Meulemans, and van Rensburg 2009).

INDIVIDUAL AND ENVIRONMENTAL NEEDS

Psychosocial Adjustment

Psychosocial adjustment, defined as an individual's response to a significant life change, is a normal part of adolescence. As children grow older, they enter a process of identity development that includes separation and individuation from parents or caregivers. The psychosocial adjustment of children entering adolescence is strongly related to parental and family factors, and the large numbers of children living with HIV in Africa that are also orphans can find this adjustment enormously difficult (Brown, Lourie, and Pao 2000; Petersen et al. 2010). Programs need to address psychosocial development and work with ALHIV to understand their family environment, to facilitate self-management of HIV, and to strengthen

their sense of competence throughout the transition process (Naar-King et al. 2009a; Petersen et al. 2010; Valenzuela et al. 2009; While et al. 2004; Wiener et al. 2009).

The familial context must also be considered and addressed when decisions related to self-care and clinical management are made, given the important role family plays in providing social support to people living with HIV (Brown, BeLue, and Airhihenbuwa 2010). Many families have been severely challenged by HIV, and many ALHIV are cared for by grandparents, elderly caregivers, or other family members. These burdens often deplete household income available to support adolescents as they transition (Nachega et al. 2010). A recent study among ALHIV in Zambia shows that many do not have strong family support, especially if orphaned and living with extended family, a key consideration when promoting self-care. Many caregivers are overstretched, unengaged, and not empathetic to adolescents' special needs. This environment may increase the vulnerability of ALHIV and may reinforce the need to focus on strengthening health systems to be able to respond to the reality facing so many adolescents (Hodgson et al. 2011). Many ALHIV rely on caregivers, who may be sick themselves, to administer and remind them to take antiretrovirals, a situation that may contribute to nonadherence and that needs to be addressed during transition (Prendergast et al. 2007).

In the Democratic Republic of Congo, youth (both HIV-positive and HIV-negative) who lost their mothers to complications associated with HIV were more likely to miss health appointments and had less adult supervision compared to youth who did not lose their mothers to HIV (Andrews, Skinner, and Zuma 2006). This has serious implications for ALHIV, and it reinforces the need to include family and caregivers in the transition process to strengthen and support the self-care skills being developed by the adolescent.

Both South Africa and Botswana have had some success in using a family model to deliver HIV care, and this can provide a supportive context to promote young people's self-management within the context of their family. Evidence shows ALHIV have stronger health outcomes when they have higher levels of parental/caregiver involvement (Naar-King et al. 2009a; Petersen et al. 2010; Scal and Ireland 2005), and that strong psychosocial support provided to familial and nonfamilial contacts are associated with higher levels of psychological coping mechanisms and adherence among ALHIV (Battles and Wiener 2002; King et al. 2009; Petersen et al. 2010; Williams et al. 2006). Additionally, the benefits of psychological interventions, peer support approaches, and social and economic support for ALHIV can lead to stronger levels of adjustment (Bachanas et al. 2001; Battles and Wiener 2002; King et al. 2009; Petersen et al. 2010). It is critical that providers understand the family structure and ensure that existing protective factors are reinforced through transition. Although this requires more resources, the benefits greatly outweigh the costs.

Psychosocial Well-being and Mental Health

Adolescents living with HIV have a higher need for psychosocial support and are at higher risk for mental health challenges compared to those uninfected due to both psychological reasons and the effects of HIV infection on neurological functioning (Bachanas et al. 2001; Brown, Lourie, and Pao 2000; Earls, Raviola, and Carlson 2008; Fielden et al. 2006; Ross et al. 2010; Steele, Nelson, and Cole 2007; Van Rie et al. 2007). Many times, psychiatric illnesses emerge for the first time during adolescence, and providers should be aware of how common the comorbidity of clinical depression and HIV is among adolescents who were infected perinatally (Battles and Wiener 2002; DeLaMora, Aledort, and Stavola 2006; Fielden et al. 2006; Patel et al. 2007; Petersen et al. 2010;

Ross et al. 2010). ALHIV face higher rates of attention deficit hyperactivity disorder, anxiety disorders, and depression compared to adolescents who do not have HIV (Battles and Wiener 2002; Fielden et al. 2006; Lee et al. 2006; Petersen et al. 2010; Ross et al. 2010; Scharko 2006). Mental health issues can result in a lower quality of life, faster progression of HIV, and poor adherence to treatment (Crepaz et al. 2008; Petersen et al. 2010; Rao et al. 2007).

Transition programs and policies should include a strong focus on mental health and should provide or refer for effective mental health and psychosocial support to improve the quality of life and well-being of ALHIV. Key models to explore include a focus on peer support and using lay counselors to strengthen the level of care for the adolescent (Petersen et al. 2010; Vaz et al. 2010).

Sexual and Reproductive Health

Sub-Saharan Africa has the highest rates of teenage pregnancy in the world, with many adolescent girls married by the age of 15 (Clark 2004; Laksi and Wong 2010). Often, female ALHIV are diagnosed upon entering antenatal care. Among boys, there is a wide range in sexual debut and little interaction between them and health and social services. Service providers at all levels who help ALHIV navigate transitions must be equipped to deal with clinical and psychological issues of sexuality and reproductive health (Clark 2004; DeLaMora, Aledort, and Stavola 2006; Ferrand et al. 2010). When children living with HIV reach adolescence, they are likely to examine their sexuality in the context of their HIV status. Many adolescents will begin to experience sexual desire and are likely to engage in intimate relationships, including same-sex relations. Real fears exist regarding disclosure, rejection, and the potential for HIV transmission to their partners. The evidence suggests that families, caregivers, and service provid-

ers should work with adolescents and provide clear facts on positive health and prevention, working to strengthen their self-esteem, sense of dignity, and self-efficacy to approach life, examine high-risk situations, and pursue their sexuality in a positive way (Brown, Lourie, and Pao 2000; Fielden et al. 2006; Wiener et al. 2009).

Throughout the transition, providers must include access to confidential sexual and reproductive health services, which includes adherence to medications to ensure low viral loads and high condom use (Prendergast et al. 2007). Referrals for family planning should be part of the transition, and ALHIV who desire to have children in the future, or who are pregnant, should be referred for safe pregnancy counseling to protect themselves and to reduce transmission to their partners and children.

Evidence recently emerged showing ART can prevent HIV transmission among discordant couples (Cohen et al. 2011). These findings increase the importance of adherence to ART and the need to provide continuous support to people living with HIV, including ALHIV, to achieve maximum viral suppression. Sexual and reproductive health counseling targeting ALHIV must address ART adherence in order to contribute to reducing the likelihood of HIV transmission during sex (The Lancet 2011a). It should be noted that these research findings apply to adults living with HIV; therefore, more research is needed to investigate whether benefits of ART as a prevention mode applies to this important population as well.

Alcohol and Substance Use

There is little data on rates of substance and drug use among adolescents in sub-Saharan Africa. However, studies among adolescents in South Africa show a strong link between substance use and a higher incidence of risky sexual behaviors (Morojele, Brook,

and Kachieng'a 2006). Programs that focus on transition must address substance use, including alcohol and other illicit substances. There is promising evidence that brief interventions, such as motivational interviewing, can be routinely included in ALHIV services to address both adherence (as discussed later) and substance abuse.

Beneficial Disclosure

HIV disclosure is a continuous process of informing an adolescent and others of his or her illness, which takes the developmental age and readiness of the child into account (WHO 2011b). The process of HIV disclosure is multidimensional and complex, and interacts with the process of psychosocial adjustment that occurs throughout the period of adolescence (Steele, Nelson, and Cole 2007). For ALHIV, disclosure can be thought of in several ways: 1) by a parent about his or her own HIV status; 2) by a parent or caregiver about the adolescent's HIV status; 3) by a parent or caregiver about the adolescent's HIV status to other family members, school teachers, or community members; 4) by an adolescent to friends; 5) by an adolescent to family members, school teachers, or community members; and 6) by an adolescent to potential sexual partners.

In particular, the disclosure of an adolescent's HIV status to other family members, community members, and school teachers must be approached with care. The primary question should be what would be the benefit of disclosure to the ALHIV and do these benefits outweigh any potential risks? There is limited data supporting the benefits of disclosure to these groups, though there may be personal individual reasons to consider (WHO 2011b). Disclosure is not a linear process; it never finishes, and it often requires simultaneous or overlapping disclosure by the adolescent to different audiences over one's lifetime.

The secrecy and cultural taboos around HIV in many African countries means the decision of parents or caregivers to tell their children is accompanied by fears related to stigma and is seldom done before identifying a strong supportive network (Daniel et al. 2007; Doku 2010; Menon et al. 2007; Petersen et al. 2010; Vaz et al. 2010). Disclosure is considered a prerequisite to transition because only when children learn their status can they transition to self-management of HIV. Evidence shows children who are aware of their status have better psychosocial adjustment than those who do not know their status. However, disclosure remains a controversial issue; when and how to disclose to children remains a struggle for most parents/caregivers and providers (Brown, Lourie, and Pao 2000; Menon et al. 2007; Petersen et al. 2010; Prendergast et al. 2007; Steele, Nelson, and Cole 2007; Vaz et al. 2010).

For ALHIV who know their status, deciding when, how, and who to disclose to is a significant part of living with HIV, and each individual must weigh the benefits and risks associated with each disclosure event (Table 3 offers a stepwise disclosure model that may be useful in practice). Amid all of these complexities, disclosure and, in particular, know-

ing one's status has been shown to have numerous benefits including higher adherence rates, increased levels of social support, higher self-efficacy, improved psychological adjustment, and decreased behavioral problems among ALHIV living in the United States and sub-Saharan Africa (Battles and Wiener 2002; Brown, Lourie, and Pao 2000; Brown, BeLue, and Airhihenbuwa 2010; Menon et al. 2007; Petersen et al. 2010; Steele, Nelson, and Cole 2007; Vaz et al. 2010; WHO 2011b, Wouters, Meulemans, and van Rensburg 2009). A recent study from Uganda showed participation in HIV-positive peer support groups led to higher self-efficacy, thus reducing feelings of stigma among ALHIV (Peterson et al. 2010). Disclosing to other positive peers in a group or in a one-on-one setting may have different consequences than disclosure in a mixed support group. Adolescents living with HIV should be made aware of the composition of such a support group. Care must be taken regarding the types of group in which disclosure takes place because it can lead to increased marginalization of the individual and his or her family (Battles and Wiener 2002; Brown, Lourie, and Pao 2000; Petersen et al. 2010; Punpanich et al. 2008; Steele, Nelson, and Cole 2007; Vaz et al. 2010; Wouters, Meulemans, and van Rensburg 2009).

TABLE 3. STEPWISE DISCLOSURE TO CHILDREN		
Early steps	**Next steps**	**Final steps**
Make sure children know: • To stay healthy they must take their medicines • When to take their medicines • How to take their medicines, including rules around when and what to eat • The name of their medicines.	*Make sure children know:* • Medicines make them healthy by increasing the strength in their bodies • As their bodies get stronger, their health problems decrease • As long as their bodies are strong, they can do whatever they want in life.	*Make sure children know:* • Their bodies become weak because of the virus • The proper terms (e.g., CD4 cells, HIV) • The truth to minimize misconceptions • How the virus is transmitted; for older teenagers talk about safer sex in a clear and direct manner • Taking medicines and going to the clinic are a lifelong commitment.
Remember: Be encouraging and give positive messages.	*Remember:* Stress the future and positive messages.	*Remember:* Be open to questions and answer all truthfully.

Source: Paediatric KITSO, Botswana-Baylor Children's Clinical Center of Excellence, Botswana Ministry of Health, and UNICEF n.d.

Loss, Grief, and Bereavement

Many children living with HIV in sub-Saharan Africa have lost one or both parents, a caretaker, relative, or other sibling to HIV (Cluver, Gardner, and Operario 2007; Daniel et al. 2007; DeLaMora, Aledort, and Stavola 2006; Earls, Raviola, and Carlson 2008; Petersen et al. 2010), and this loss and resulting bereavement can impact their transition from pediatric to adult or adolescent care (Brown, Lourie, and Pao 2000; Petersen et al. 2010). There is not a significant amount of evidence on how ALHIV experience grief and how this may impact transition in the wide and diverse range of African countries and cultures (Cluver, Gardner, and Operario 2007; Daniel et al. 2007). The transition process must acknowledge and monitor grief to ensure strong psychosocial support and counseling systems are in place (Cluver, Gardner, and Operario 2007; Earls, Raviola, and Carlson 2008; King et al. 2009; Petersen et al. 2010).

CLINICAL NEEDS

HIV Testing

As mentioned previously, many children in sub-Saharan Africa may not know their HIV status when they reach adolescence (Ferrand et al. 2010; Menon et al. 2007). Some may be in HIV care, including taking ART, but have not been informed about their HIV status or they may be slow progressors who receive clinical treatment for infections and illnesses related to HIV but have never been tested. Many barriers exist to HIV testing because parental or guardian consent is needed in most countries to test minors (Ferrand et al. 2009a). As a response to this, South Africa recently implemented a controversial policy allowing children aged 12 and older to consent to an HIV test without parental or guardian consent (The Lancet 2011b). There are also recommendations to introduce routine HIV screening in infant/child immunization clinics to ensure they are placed in HIV care before

reaching adolescence (Coovadia and Mantell 2010). However, at the center of every HIV testing program is the need to ensure that confidentiality, consent, and counseling are provided, and all testing for adolescents should include referrals to post-test support services.

Self-management of Clinical Care

Increased, progressive self-management of HIV care, which includes adherence to treatment and retention in care and support programs, is required during transition and is the ultimate outcome of transition (Ferrand et al. 2010). Many ALHIV and their caregivers hesitate to leave pediatric care for adult care because leaving a known setting and trusted providers can produce anxiety (Machado, Succi, and Turato 2010; Reiss, Gibson, and Walker 2005). During transitions, ALHIV have to increasingly become more responsible for making clinical decisions in a new environment. If the adolescent is coming from a pediatric care program, the transition may also include the stress associated when leaving a known and safe relationship for an unknown one. To minimize stress, the transition should use an age and developmentally appropriate approach of increased self-management and patient autonomy. There is a range of difference between middle and late adolescence, and the process must be flexible enough to support ALHIV to adhere to their medication and follow-up schedule, while also promoting personal growth. Additionally, some ALHIV may be pregnant or have children and may need to simultaneously learn to manage their own care as well as care for a child. Table 4 provides information to consider in building the capacity of ALHIV to manage their care. When reviewing this table, it is important to note that many of the services mentioned may not be available at all levels of care, if at all, and may require a referral.

Many times, the actual disclosure of a child's status may usher in the process of self-management

TABLE 4. SELF-MANAGEMENT TIMELINE

Age	Somewhere between 8–12 "Envisioning a Future"	Somewhere between 13–16 "Working toward Responsibility"	Somewhere between 17–19 "Capacity to Transition"
Individual growth and environmental support: Encouraging healthy decisions			
Psychosocial support	• Link to relevant support groups and programs	• Link to relevant support groups and programs	• Link to relevant support groups and programs • Support mentorship of younger positive adolescents
Sexual and reproductive health, positive health, and prevention	• Answer any questions that emerge honestly and truthfully	• Link to adolescent-friendly reproductive health provider and clinics, review sexuality issues and safe sex practices • Refer for regular sexual health check-ups • Discuss HIV prevention methods	• Continue sexuality conversations, encourage questions about HIV, pregnancy, and sexuality • Refer for regular sexual health check-ups • Discuss HIV prevention methods
Substance use	• Discuss substance use and how it can impact health	• Discuss the links between sexually risky behaviors, substance abuse, and poor health outcomes; assess if using substances and what triggers use	• Discuss the links between sexually risky behaviors and substance abuse, and poor health outcomes; assess if using substances and what triggers use
Future planning	• Initiate conversation about future goals (work, school, etc.)	• Promote peer education opportunities • Connect ALHIV with relevant nongovernmental organizations	• Connect ALHIV to job training, vocational training, and continued education opportunities
Clinical support: Providing or facilitating referrals for needed services			
Self-care	• Support caregivers to disclose to the adolescent if not already done • Talk to the child to start mapping out the transition timeline after disclosure	• Build a schedule/calendar with the adolescent to strengthen adherence to treatment and retention in support programs • Discuss and address transportation barriers and other issues that hinder adherence to ART and clinical visits	• Reinforce responsibility in taking medications and keeping appointments
Clinical management	• Begin to explain medications and reinforce adherence messages for those already on ART • Talk about adherence issues • Link to counseling (including lay or peer) for any mental health issues	• Talk to the adolescent about diagnosis, medications, and adherence • Talk to adolescent about how to seek clinical care for symptoms or emergencies • Link to counseling (including lay or peer) for any mental health issues	• Review clinical history with the adolescent • Help identify appropriate adult providers/clinics • Solicit questions about care, treatment, and potential future changes in treatment • Link to counseling (including lay or peer) for any mental health issues

Note: These are recommended and should be adapted to the level of the health system at which the adolescent routinely receives care. In many cases the same providers care for both pediatric and adult clients at the same facility. Source: Hodgson et al. 2011; Jacob and Jearld 2007; Reiss, Gibson, and Walker 2005.

(Chenneville, Sibille, and Bendell-Estroff 2010; Ross et al. 2010). There is little information on the factors associated with strengthening autonomy and responsibility for care among ALHIV in sub-Saharan Africa; however, a range of studies show that issues related to self-efficacy, coping, resiliency, locus of control, collective/familial support, education level, and the power of disclosure are all key considerations when crafting policies and programs to successfully transition ALHIV from pediatric- to adult-centered care (Bachanas et al. 2001; Battles and Wiener 2002; Brown, Lourie, and Pao 2000; Earls, Raviola, and Carlson 2008; Kabore et al. 2010; Kmita, Barnanska, and Neimiec 2002; Meijer et al. 2002; Menon et al. 2007; Petersen et al. 2010; Vijayan et al. 2009; Williams et al. 2006; Wouters, Meulemans, and van Rensburg 2009).

Additionally, as children infected perinatally with HIV reach adolescence and adulthood, the likelihood that they will receive second- and third-line medications grows, reinforcing the importance of adherence to reduce resistance and also to keep viral load low (Pursuing Later Treatment Options II Team 2011). This will become a larger issue for this population going forward, and it therefore must be addressed during the transition process.

Adherence

Adherence, defined as compliance with clinical treatment and care regimes, is a difficult goal for many ALHIV and is intimately linked to their ability to manage their own diagnosis and care. In sub-Saharan Africa, ART rates remain low. Only 47 percent of those clinically eligible for ART are able to access it; of those, children comprise only 23 percent (WHO 2011a). Among those on ART, the complexity of routinely accessing clinical services and adhering to daily drug regimens makes nonadherence common (DeLaMora, Aledort, and Stavola 2006; Krummenacher et al. 2011; Naar-King et al. 2009b; Prendergast

et al. 2007; Rao et al. 2007). Optimal ART adherence, typically measured as 95 percent or greater, is difficult for most people to attain, and recent evidence shows ALHIV have lower rates of adherence to ART than adults in Southern Africa. This results in lower rates of viral suppression and higher rates of viral rebound after initial suppression (Nachega et al. 2009). For many ALHIV infected perinatally, the many harsh side effects make stopping the medications seem a viable option. This may become less of an issue as ART regimens become more manageable and have less side effects (Foster et al. 2009; Naar-King et al. 2009b; Prendergast et al. 2007; Vijayan et al. 2009). Additionally, social, economic, structural, and individual barriers to treatment adherence for ALHIV are numerous in resource-constrained settings.

A recent cohort analysis from Uganda that included ALHIV demonstrated a decline in adherence rates over the one-year time period studied. Many of the factors impacting adherence are outside of the adolescent's control, such as stockouts, lack of access to the clinic, and transportation difficulties (Nachega et al. 2010). In a recent South African study among ALHIV, a multitude of factors were associated with poor adherence, including depression, pill burden, advanced HIV status, alcohol use, dropping out of school, side effects, and the complications associated with a day-to-day routine (Nachega et al. 2009). Stigma and disclosure also play a large role in nonadherence among ALHIV. There remains a need to determine the barriers to adherence that pertain to ALHIV, and to perinatally infected ALHIV specifically, and adapt transition programs to minimize them (Nachega et al. 2010). Program planners and policymakers must consider multiple variables when promoting adherence and self-care via transition (see Table 5).

Mental health problems, poor psychosocial well-being, and self-stigma are also associated with lower adherence rates among ALHIV (Nachega et al. 2009).

TABLE 5. MULTIPLE VARIABLES TO ADDRESS WHEN TRANSITIONING TO SELF-MANAGEMENT		
Individual	**Environmental**	**Facility/Clinical**
• Current age of adolescent • Alcohol use • Advanced HIV status • Day-to-day life complications • Unable to continue school • Depression • Poverty • Stigma	• Transport/access to clinic • Poverty • Stigma	• Pill burdens • Stockouts of medicines • Side effects • Poverty • Stigma

Source: Nachenga et al. 2009.

All programs that focus on transitions among perinatally infected adolescents must stress the importance of adherence to a daily and complex drug regimen and routine clinical monitoring. Some evidence exists detailing the clinical benefits of brief interventions to improve adherence rates among ALHIV. Providers who initiated four sessions of motivational interviewing using the information, motivation, and behavioral model strengthened the ability of ALHIV to manage their diagnosis, and improved adherence (Amico 2011; Krummenacher et al. 2011; Naar-King et al. 2009b, Rongkavilit et al. 2010). This approach moves a client along a continuum from pre-contemplation, to contemplation, to preparation, to action, and to maintenance in order to minimize risk behaviors associated with low adherence. Among youth, it has been shown that a focus on motivation and positive intrinsic behaviors (e.g., values and satisfaction) is more effective than on extrinsic factors (e.g., guilt and rewards; Dilorio et al. 2008; Naar-King et al. 2009b; Rongkavilit et al. 2010; Suarez and Mullins 2008).

IDENTIFY BARRIERS TO TRANSITION

Overlapping barriers to transition exist at the provider, client, and family levels and must be addressed to minimize interruptions in care and treatment. Many health systems have little to no response to this emerging group, and policies remain nascent at best. Communication between all parties remains one of the largest barriers and should be prioritized throughout transition. See Table 6 for an outline of many of the barriers to transition.

PERSONAL/ENVIRONMENTAL BARRIERS

Adolescent Living with HIV

At the beginning of the transition process, adolescents may lack some key skills, traits, and knowledge necessary to help them navigate their own medications, adherence, social support, and relationships. Because adolescents mature at different rates, the transition process should be flexible and individualized, with a goal to enroll and maintain them in clinical care and social support programs. Evidence shows that younger adolescents are more likely to adhere to their medications, with adherence levels decreasing over time (Mellins et al. 2003; Naar-King et al. 2009b; Williams et al. 2006). Lower rates of adherence in older adolescents is likely to be caused by being given more responsibility for their own medication management without having proper transition support (Williams et al., 2006).

Family/Caregiver

Family strengths should be evaluated before transition begins, and families should be encouraged to

continually redefine family roles, allowing for ALHIV to have more autonomy as they grow and develop. This flexibility will help ensure that strengths and coping skills are optimized through the process while maintaining appropriate and responsive levels of support. Opportunities for paid and volunteer work can facilitate leadership skills among both adolescents and their caregivers, and high involvement of both can maximize outreach to hard-to-reach clients.

Environment

The environment surrounding ALHIV may contain numerous barriers associated with transition, including stigma, lack of supportive community programs and services, and lack of family support. Pro-

viders should work to understand the adolescent's environment to identify and maximize protective factors that will support transition and to minimize the negative influences that will make transition more difficult. Using a person-in-environment approach allows for ALHIV to cultivate a stronger ability to solve problems, realize their potential, and enhance their lives. Examining the surrounding environment can help reduce social and systematic barriers and remove obstacles to transition.

CLINICAL BARRIERS

Provider

In many countries, adolescent HIV care is not a specialization, and there is no large cadre of health

TABLE 6. BARRIERS TO THE TRANSITION OF HIV CARE AND OTHER SERVICES					
Individual	**Environmental**		**Facility/Clinical**		
Adolescents living with HIV	*Family/ Caregiver*	*Community*	*Providers*	*Health services*	*Health policies*
• Not accessing services • Not attending services • Not understanding requirements • Not applying information and support • Not aware of diagnosis • Stress of diagnosis • Self-stigma • No transportation funds • Resists the transition	• Not promoting adolescent autonomy • Not engaged in the care of the adolescent • Not able to provide full support for transition • Stretched thin by not having enough resources to support the family • Resists the physical transition	• Unsupportive social setting • Stigma • Peer pressure • Unsupportive or absent family network • No universal family counseling and testing • Weak institutional support • Weak community support	• Pediatrics difficult to let go • Weak understanding of what is needed to transition • Adult providers do not understand adolescents' holistic needs • New provider not comfortable with adolescents • Unable to plan with adolescents, services, and families for transition • Lack of communication between pediatric and adult providers • Resists the transition	• Not adolescent friendly • Medicalization of clinics • Information is poorly given • Risk of loss to follow-up • Not all adolescents have access • Abrupt transfer with no prior preparation • Adult services not adolescent friendly • Differences between pediatric/family care and adult/ individual care	• Lack of formal policies and definitions • Lack of transition definition • Lack of family-focused counseling and testing policies and protocols

Note: These are recommended and should be adapted to the level of the health system at which the adolescent routinely receives care. In many cases, the same providers care for both pediatric and adult clients at the same facility. Source: Hodgson et al. 2011; Machado, Succi, and Turato 2010.

professionals trained to work on adolescent-specific care issues. Being sensitive and knowledgeable about the special needs of adolescents is important, as is maintaining a client-centered focus that promotes the patient–provider relationship. Providers should treat youth with respect and in a nonjudgmental manner, with privacy and confidentiality at the forefront of all interactions. Many adolescents may not know their status, and disclosure is often a first step. Upon learning one's status, care should begin with prioritizing the client's well-being. It is important for providers to maintain realistic expectations while promoting self-management. Because HIV is surrounded by stigma and discrimination, providers must be welcoming and open, and must also be able to understand and be empathetic to the complex needs of ALHIV. Providers at all levels of service delivery should talk to their clients about the transition and should co-create an individualized self-care transition plan. Pediatric providers must discuss and promote personal development of the adolescent and communicate with adult providers to ensure a smooth transition. Providers should think of their role as advocates for ALHIV to encourage and promote the journey to self-care.

Health Systems

As this large population of perinatally infected adolescents moves through the health system, there is an opportunity to strengthen the integration of adolescent health services at all levels, including policy, services delivery, outreach, and management. Systems should develop standards for adolescent care that reflect the opinions and advice of ALHIV and their family/caregivers. Adolescents need to be comfortable receiving care at health facilities and in community services, and this is particularly true for many who are concerned they will not be welcome if they become pregnant (Schuster 2010). Health systems should have strong bidirectional refer-

rals and linkages to identified community support services. South Africa has a National Adolescent Friendly Clinic Initiative accreditation program to improve the quality of adolescent health services at the primary care level and to strengthen the public sector's ability to respond to adolescent health needs. A recent evaluation of this effort showed that setting standards for adolescent care using adolescent-friendly criteria improves the quality of services provided to this group (Dickson, Ashton, and Smith 2007).

Health Policies

The lack of a clear adolescent health policy that includes ALHIV is the key barrier at the policy level across countries. A first step is to acknowledge the need for and actually define self-managed care transition, including necessary and essential services. Additionally, having perinatally infected children reach adolescence without knowing that they are infected is all too common an occurrence. Therefore, HIV testing and disclosure guidance should be standardized with family and pediatric counseling, and testing should be promoted and supported at the policy level. When individuals are diagnosed with HIV, family testing should be encouraged.

WHAT DOES TRANSISTION LOOK LIKE?

Frameworks based on evidence are essential; however, the existing evidence for transition is minimal. This technical brief provides needed information and outlines key guiding principles to follow when building a strong framework for transition. Transition should focus on resiliency: identifying and building on the strengths of the individual, the family/caregiver, and the health care providers throughout the process. Transition should begin at the moment

of diagnosis and should provide hope as providers, adolescents, and their caregivers plan their future.

TRANSITION IS A PROCESS

Transition needs to be purposeful and planned, accounting for developmental age and client readiness (Fair, Sullivan, and Gatto 2010; Gilliam et al. 2010). There is not a "right time" for transition, and it does not occur with one meeting. It usually follows extensive discussions between ALHIV and their current and future caregiver(s) over a number of years. Flexibility will ensure those involved in the process can recognize and respond to the unique needs of ALHIV. Transition should be supported, thoughtful, and guided by a plan that is developed by ALHIV in collaboration with families/caregivers and providers. There is no set time period for transition, but literature and practice both stress that the transition should adopt a resiliency approach that identifies key risk and protective factors surrounding the physical, psychological, and social issues facing vertically infected ALHIV. This approach is particularly relevant in low-resource settings because the resilience model looks at what exists, examines the protective factors that help individuals and their families cope with HIV, and works to minimize risk factors and situations. This approach moves away from a deficit perspective and identifies strategies that work and help adolescents and caregivers/families negotiate risk (Evans 2005; Fraser and Galinsky 2004).
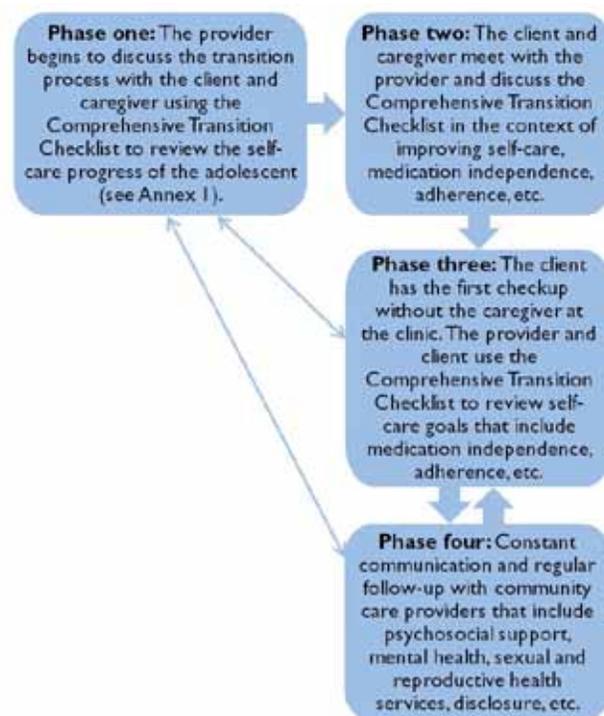
The transition is a process that includes preparation, which optimally includes adolescent support. The model should be flexible and progressive, allowing the adolescent to take on more and more responsibility for his or her care. Mistakes will be made; however, the process should focus on building on a series of wins and increasing the resilience of ALHIV to reinforce their growth (Ferrand et al. 2009b; Machado, Succi, and Turato 2010; Menon et al. 2007; Petersen et al. 2010). Transitions can

be celebrations of life and should be treated as rites of passage.

MINIMUM PACKAGE OF SERVICES

Developing a minimum package of services must include a clear plan for a transition to help adolescents progress toward self-management. Table 7 outlines an adaptation of a transitional plan that was recently developed to guide transitions in the United States. The adaptation could be used in sub-Saharan Africa where the same set of providers may work with all those living with HIV—adolescents, children, and adults. Bidirectional relationships that encourage communications among clients, families/caregivers, and their providers are critical throughout transitions (Maturo et al. 2011), and the model has bidirectional arrows to reinforce the connection between providing clinical and psychosocial care.

TABLE 7. ADAPTATION OF THE "MOVIN' OUT" TRANSITIONING MODEL

Phase one: The provider begins to discuss the transition process with the client and caregiver using the Comprehensive Transition Checklist to review the self-care progress of the adolescent (see Annex 1).

Phase two: The client and caregiver meet with the provider and discuss the Comprehensive Transition Checklist in the context of improving self-care, medication independence, adherence, etc.

Phase three: The client has the first checkup without the caregiver at the clinic. The provider and client use the Comprehensive Transition Checklist to review self-care goals that include medication independence, adherence, etc.

Phase four: Constant communication and regular follow-up with community care providers that include psychosocial support, mental health, sexual and reproductive health services, disclosure, etc.

Note: The comprehensive transition checklist mentioned in the table is included in Annex 1. Adapted from Maturo et al. 2011.

TRANSITION-GUIDING PRINCIPLES

DEVELOPMENTAL APPROACH AND FOCUS ON TRANSITION READINESS

Transition proceeds at different times for different individuals, but the recommendation is to start the process early or as soon as the child knows he or she is HIV-positive. The transition towards self-care should include steps toward helping the child understand the diagnosis and the requirements needed to stay healthy while also examining and talking about his or her hopes and fears for the future. As adolescence is a time marked by continuous change, the transition to self-care and in some cases to adult services in a different clinical setting, should begin during a time of stability, and when the adolescent is chronologically, developmentally, behaviorally, clinically, and psychologically ready. Physical transition should take into consideration the capacity of the identified adult clinic to meet the needs of ALHIV. To help ALHIV navigate new health settings, he or she should be supported to talk about the process and develop a timeline with his or her provider, family, and peers. Transition should proactively assess the client's progress and develop coping mechanisms and strategies to address potential or real barriers and stressors associated with the process.

ADOLESCENT CENTERED AND ADOLESCENT LED

Care programs should be designed with high levels of involvement and participation from the patients. Transitional services should be age and developmentally appropriate and should promote self-management skills that include aspects of self-determination, psychosocial support, and peer support to maximize their responsibility in a realistic

manner (Earls, Raviola, and Carlson 2008; Laursen 2000; Martinez et al. 2003; Miles, Edwards, and Clapson 2004; Petersen et al. 2010; Punpanich et al. 2008; Rao et al. 2007; Schenk et al. 2010; Vaz et al. 2010; While et al. 2004). The lack of active and meaningful participation of ALHIV in development, implementation, monitoring, and evaluation of many existing programs is a noted weakness.

The most successful programs cultivate high levels of participation and include peer support mechanisms for ALHIV (Earls, Raviola, and Carlson 2008; Martinez et al. 2003; Menon et al. 2007; Petersen et al. 2010; Punpanich et al. 2008; Rao et al. 2007; Ross and Cataldo 2010). Table 8 discusses effective ways to include ALHIV in the process of transition.

TABLE 8. COMMON AREAS TO INCREASE PARTICIPATION OF ALHIV IN THE TRANSITION PROCESS	
Actions to take	**Where to implement**
• Form an ALHIV transition advisory board • Create a transition mentorship program (older adolescents mentor younger) • Engage ALHIV in research, monitoring, and evaluation • Allow ALHIV to be decision makers • Engage ALHIV in communications, advocacy, and publicity • Engage ALHIV as service quality consultants • Engage ALHIV in administration, management, and program planning • Support ALHIV peer promotion/education and social networks • Engage ALHIV in community outreach • Engage ALHIV as trainers • Engage ALHIV as staff or volunteers.	Any of the actions may be implemented at a variety of care settings. The types of programs where these actions may be relevant include: • HIV clinical services • HIV community and family services • Policy making actions/programs • HIV advocacy efforts/programs. Within a single program, activities may be implemented at multiple service delivery sites, using consistent approaches and messages.

Source: Family Health International 2005.

MULTIDISCIPLINARY PROGRAMS

HIV services engaging ALHIV should strive to be multidisciplinary in order to meet their broad and complex health and psychosocial needs (Andrews, Skinner, and Zuma 2006; Brown, Lourie, and Pao 2000; Earls, Raviola, and Carlson 2008; Ferrand et al. 2009b; Johnson et al. 2003; Lee et al. 2006; Petersen et al. 2010; Punpanich et al. 2008; Ross et al. 2010; Steele, Nelson, and Cole 2007; Wiener et al. 2009). Evidence strongly supports a comprehensive, multidisciplinary approach that engages families to best meet the clinical, psychological, and social needs of ALHIV. A multidisciplinary approach should strive to have clinical care as well as case management, social services, and mental health support. Case management is not new to HIV care; however, the needs of vertically infected ALHIV are different than those who are newly infected, and a case management approach can provide stronger linkages to the needed health, social, and psychological services at the facility and community levels (Bachanas et al. 2001; Brown, Lourie, and Pao 2000; Earls, Raviola, and Carlson 2008; Naar-King et al. 2009b; Ross et al. 2010; Tolle 2009). Specially trained, supported, and supervised case management services are regularly mentioned as a way to best meet the complex and multiple needs of all ALHIV (Brown, Lourie, and Pao 2000; Fair, Sullivan, and Gatto 2010; Johnson et al. 2003; Kabore et al. 2010; Miles, Edwards, and Clapson 2004).

CONTINUITY OF CARE WITHIN THE FAMILY/CAREGIVER CONTEXT

The role of family and caregivers is constantly redefined during an adolescent's transition to self-care. Sometimes, over-engaged family members can create barriers to achieving self-care, whereas at other times, caregiver involvement is crucial to a young person's success. Programs based on a family-centered model of care are most promising in achiev-ing optimal continuum of care for transitioning AL-HIV (Fair, Sullivan, and Gatto 2010; Miles, Edwards, and Clapson 2004; Petersen et al. 2010; Vaz et al. 2010; Wiener et al. 2009). Kovacs, Bellin, and Fauri (2006) define family-centered care as a partnership with the patient and his or her family operating on two levels to address the clinical and the psycho-social needs of a client. Family-centered care can identify strengths and respond to the specific concerns of families. Service providers should employ family-centered care that targets the specific needs of adolescents and their families/caregivers, taking their different developmental needs and household situations into account (Johnson et al. 2009; Li et al. 2010; Miles, Edwards, and Clapson 2004; Petersen et al. 2010; Prendergast et al. 2007; Punpanich et al. 2008; Vaz et al, 2010; Wiener et al. 2007, 2009). It is important that health care services build relationships with ALHIV and their primary adult caregivers because both are key to ensuring strong continuity of services. Because HIV affects individuals, families, and communities, all levels of care should be addressed during transition (Cook and White 2006).

HIV service providers and policymakers should promote models that examine and maximize resiliency within the individual and the family, and recognize that there is no single answer that will apply for all ALHIV and their families. Also, as ALHIV reach 19 years and older, they should be more able to make decisions on self-care and be less reliant on family members. Throughout the process, providers should work with ALHIV to identify specific risk and protective factors as they occur and document any commonalities to address and minimize the challenges being faced.

HOLISTIC, FLEXIBLE, AND FUTURE FOCUSED

Transition should be holistic because adolescence is itself a life transition. Employing a focus on the

future, transition should identify opportunities, requirements, and expectations of how to live with HIV. Throughout this process, mental health and social support must be provided in tandem with clinical components. Recent evidence from Zambia shows that the clinical aspects related to adolescent care are more frequently provided and stronger than the social aspects, noting the need to increase linkages with social programs during transition (Hodgson et al. 2011). The diversity of the physical, social, and psychological needs of ALHIV reviewed here point strongly to the need to integrate stronger psychological and social services into existing clinical care and treatment for ALHIV (Earls, Raviola, and Carlson 2008; Kabore et al. 2010; Menon et al. 2007; Petersen et al. 2010; Schenk et al. 2010). The provision of holistic and multidisciplinary services for ALHIV remains lacking globally, with minimal effort made to address these gaps in sub-Saharan Africa (Earls, Raviola, and Carlson 2008; Ferrand et al. 2010; Gilliam et al. 2010; Petersen et al. 2010). Long-term and systematic changes are needed in sub-Saharan Africa to address resource gaps and increase service coverage for this population.

TRANSITION PROGRAMMING: WHAT EXISTS

EVIDENCE OF GOOD PRACTICE

In general, comprehensive services to support adolescents as they transition to self-care are not the norm, and adolescents remain poorly served (Ferrand et al. 2009b). However, there is a growing body of evidence to guide programs and policy to best respond to the comprehensive needs of ALHIV in sub-Saharan Africa, some parts of which may be replicable in different settings.

The **Botswana Baylor Children's Clinical Centre of Excellence** (Botswana-Baylor), a partnership between the Government of Botswana and the Baylor International Pediatric AIDS Initiative, has an adolescent program that addresses the unique needs of ALHIV, primarily those who were perinatally infected. The clinic opened in 2003 for children living with HIV and their families; at the time, they had a few adolescent clients. Now, these children are reaching adolescence, and services are provided for over 600 adolescents. Services include clinical treatment, with specialized care and support programs to approach puberty and adolescence positively. Bimonthly adolescent forums are held with social workers and/or psychologists, leading all staff through the most challenging adolescent cases, with a focus on how best to deal with psychosocial issues. The multidisciplinary forum includes physicians, nurses, psychologists, social workers, and auxiliary staff. Through the adolescent forum and other innovative interventions, the program strives to strengthen staff capacity to provide the highest possible standard of care for ALHIV. Additionally, Botswana-Baylor partners with nongovernmental organizations at the local level to decentralize psychosocial care and support interventions for adolescents, via the Botswana Teen Clubs. A peer support intervention, the **Botswana Teen Club** network, has eight sites in Botswana and continues to grow. This is a program through which over 600 ALHIV gather to "build positive relationships, improve their self-esteem, and acquire life skills through peer mentorship, adult role-modeling, and structured activities, ultimately leading to improved clinical and mental health outcomes as well as a healthy transition into adulthood" (AIDSTAR-One n.d.b).

Level of Evidence: Programmers should consider adapting relevant aspects of this model to their context, as appropriate. Noting this model is comprehensive, replication of the entire program may

not be feasible in most settings. No randomized control trial exists specifically looking at the impact of the Botswana Teen Club on perinatally infected adolescents. However, expert opinion (Baylor International Pediatric AIDS Initiative 2010) and teen-aged participants rank the program as useful.

In Zimbabwe, the **Zvandiri Programme** (*Zvandiri* means "as I am") provides psychosocial support to ALHIV. Operational for over five years, services are decentralized to more than 20 communities in the Harare region. Services use bidirectional referrals from clinics to community services to strengthen the care and support of ALHIV. Zvandiri ensures strong mental health, life skills training, vocational training, one-on-one counseling, and adherence support linking to hospitals and clinics that provide ALHIV treatment services (Southern Africa HIV and AIDS Information Dissemination Service 2010). Table 9 details the Zvandiri Program model.

Level of Evidence: Programmers should consider adapting this model to their context and, at minimum, offer some level of psychosocial support

delivered by lay and peer counselors. No randomized control trial exists specifically looking at the impact of the Zvandiri Program on perinatally infected adolescents. However, Zvandiri is regarded as a best practice based on the Southern African Development Community framework of HIV best practices (Southern Africa HIV and AIDS Information Dissemination Service n.d.).

The successful **Collaborative HIV Prevention and Adolescent Mental Health Program** (CHAMP+) provides multidisciplinary care for adolescents in the United States and has been successfully adapted to be used with ALHIV in South Africa (AIDSTAR-One n.d.a; Petersen et al. 2010). Providing family-based HIV prevention and mental health treatment to a wide range of target populations that include ALHIV, the intervention can be applied in many different contexts, yet adaptation must be informed by local knowledge and empirical evidence to ensure cultural congruence. Using a person-in-environment approach, the program works to understand complex family processes and cultural contexts, regardless of the microlevel theories used to facilitate behavior change. The

TABLE 9. THE ZVANDIRI MODEL FOR PSYCHOSOCIAL CARE FOR ALHIV IN ZIMBABWE	
Early steps	**Next steps**
Clinical care: • Diagnosis • Monitoring • Management of opportunistic infections • Counseling • ART • Prevention of mother-to-child transmission	**Community care:** • Support groups: psychosocial support, counseling, positive living education, nutrition, gardens, treatment literacy • Community outreach: psychosocial support, counseling, home-based care, positive living education, child tracing, treatment literacy, caregiver training, adolescent sexual and reproductive health • Adherence supporters: psychosocial support, counseling, home-based care, positive living education, child tracing, treatment literacy • Support and training center: psychosocial support; counseling; home-based care; positive living education; adolescent-led psychosocial support training; adolescent-led information, education, and communication materials; recreation activities; skills training; education and medical assistance.
Providers: • Ministry of Health and Child Welfare • City Health Private Clinics	**Provider:** • Zvandiri Community Care and Support Model

program emphasizes building social networks for support, such as protective peer support networks to strengthen adolescent autonomy, which is key to transitions (Bhana et al. 2010).

Level of Evidence: Programmers should consider adapting this model to their context and, at minimum, offer some level of psychosocial support delivered by lay and peer counselors. No randomized control trial specifically looking at the impact on perinatally infected adolescents exists. However, CHAMP-South Africa has one randomized control trial that showed the program strengthened protective factors that are associated with less risky behavior for adolescents in South Africa (Bell et al. 2008).

FINAL RECOMMENDATIONS

The multifaceted health and psychosocial needs of ALHIV should have a high priority on the political agenda. Until this happens, interventions that remain accessible among this population in the higher resource countries will remain inaccessible to 90 percent of children living with HIV in resource-constrained settings (WHO 2011a). In addition to evidence-based approaches, findings such as the recent evidence that supports using ART to prevent HIV transmission among discordant couples (Cohen et al. 2011) should be considered and addressed by all transition programs. However, it should be noted that the research to date has focused on adults.

Adolescents' unique needs described throughout this brief need to be taken into account when considering the implementation of ART as prevention strategies and approaches. A critical need is to focus transition programs on strengthening the ability of young women and men to manage their own care to better understand the benefits to themselves and others of taking ART and adhering to the regimen (The Lancet 2011a). Despite the complexity associated with transitions, much more can be done to ensure the process is smooth, to promote self-management to improve ALHIV own health, and to contribute to reduced transmission and new infections.

What follows are specific, actionable recommendations for policymakers and program planners that provide a broad framework for consideration. As individuals work in collaboration to develop transition programs, every effort should be made to take into consideration these recommendations and to make decisions about how to include them in their plans based on the specific situation and context. Recommendations are provided in broad areas: program/service delivery, training and capacity building, policy, and monitoring and evaluation. General recommendations are provided, as well as specific recommendations for personal-/community-based programs and clinical efforts where relevant. It is critical that planners and implementers address the recommendations in each of these categories to ensure comprehensive, sustainable programs are implemented.

PROGRAM/SERVICES RECOMMENDATIONS

General recommendation	Recommendations for personal-/ community-based programs	Recommendations for clinical programs
Ensure services are flexible, client-focused, and adolescent-friendly. Review and capitalize on the resiliencies of adolescents and their families when developing services.	Initially, services should be family and adolescent focused, which includes peer support services for both the adolescent and the caregiver/families, and flexible to adapt to the adolescent's growing autonomy.	If a physical transition will occur, pediatric providers and clinics must make transitions a standard of care and develop a transition roadmap, detailing how the process occurs. If the child is transitioning to adult care within the same clinic, services must understand the unique nature of adolescent care and work with the adolescent to transition to self-care.
Disclosure must be a prerequisite for transition. Establish a clear timeline for transition to occur to ensure the process is facilitated by the provider, the adolescent, and his or her family/caregiver to promote adolescent independence.	Do not physically transfer ALHIV until they are able to independently attend adult clinics and are past the growth/puberty stages, as per country guidelines. As an ALHIV transitions to self-care, make sure that the provider works with the client to promote autonomy in a developmentally staged manner (use Annex 1 Comprehensive Transition Checklist).	Designate one pediatric and one adult provider to be in charge of transition. Develop and support strong communication and connections between these two providers. If the same provider, encourage self-care (use Annex 1 Comprehensive Transition Checklist) and make linkages with appropriate community care services.
Cultivate high levels of adolescent participation and be youth owned.	Implement strong referral networks to support the multiple needs of ALHIV. Link adolescents with appropriate adolescent materials and peer networks. (such as those available at http://archive.k4health.org/toolkits/alhiv)	Review and monitor transition with the client and family members throughout the process. Implement responsive, robust systems to identify early defaulters and loss to follow-up.
Include a multidisciplinary approach to ensure the unique needs of adolescents are covered to the extent possible.	Integrate strong psychological and social services into existing clinical care and treatment for adolescents. Link to existing services and programs for orphans and vulnerable children.	Ensure adolescent and family counseling and testing services are available and accessible. Provider-initiated counseling and testing should be offered to families after one member is diagnosed with HIV. Make referrals for family planning and safe pregnancy counseling.

TRAINING/CAPACITY BUILDING RECOMMENDATIONS

General recommendation	Recommendations for personal-/community-based programs	Recommendations for clinical programs
Develop quality improvement standards that are targeted to improve the process of transition.	Provide adolescents with training on the process of transition, which will include comprehensive transition checklists (see Annex 1) to support their path to self-management. Training and capacity building should be a continuous process.	Develop human resource systems that offer adolescent health trainings for providers to strengthen preservice, in-service, and refresher trainings that focus on caring for the special needs of adolescents.
Develop clear training requirements for adolescent care and continuous supervision structures that provide supportive supervision approaches for those providing care and multidisciplinary services for ALHIV.	Provide training to the caregiver and family on the process of transition, including checklists to transfer responsibility over to the adolescent throughout the process (see Annex 1). Develop a cadre of trained peer educators and supportive partners who have gone through the transition process to work directly with adolescents. Explore links and connect with orphans and vulnerable children trainings in-country.	Provide training for community health workers and for the adult program support team who will receive transitioned adolescents in the adult care facilities.

POLICY RECOMMENDATIONS

General recommendations

- Define adolescence and recognize adolescents' need for health care/specialization, taking into account evidence, best practice, legal norms, and local culture and customs.
- Develop a common definition of transition for adolescents with chronic illnesses, such as HIV.
- Implement clear policies on the age of consent for HIV testing to reduce barriers for adolescents.
- Develop self-management transition interventions as a standard of care for children living with HIV.
- Cost, budget, and link adolescent health programs to funding at the country level.
- Support advocacy and multisectoral partnerships outlining country-specific priorities and specific goals within governments (ministries of health, youth and vulnerable children, and social support, etc.), among civil society, and donor governments.
- Provide preservice and ongoing health and community care training specific to ALHIV, as part of the standard package of training for providers.
- Establish clear data collection procedures for this age group.

MONITORING AND EVALUATION RECOMMENDATIONS

General recommendations

- Develop country-appropriate routine monitoring indicators for transition for both perinatally and behaviorally infected ALHIV that include predictors for success, using clearly defined indicators, along with numerators and denominators as appropriate.
- Where routine data on adolescents is not being collected, establish routine data collection that is integrated within national systems. This will help to provide accurate estimates of populations in need (adolescents aged 10 to 19). Data should be disaggregated for adolescent age ranges with young adolescents at 10 to 14 years and older adolescents from 15 to 19 years.
- Advocate for the disaggregation of coverage estimates by age group and regions (e.g., rural versus urban).
- Monitoring and evaluation frameworks should describe data analysis and use plans developed for the national, regional, district, community, and facility levels.
- Develop a research agenda and conduct studies/operations research to address barriers and develop good practice models at the country level. Plans should include both quantitative and qualitative studies that answer key service delivery and health outcome questions for ALHIV.

ANNEX I

COMPREHENSIVE TRANSITION CHECKLIST

This checklist outlines the minimum package of services for ALHIV and is provided as guidance for the provider to review with the adolescent and the family/caregiver and to help establish self-management goals. The column on the left describes the expected behavior and the next column describes the age range in which that behavior is expected to take place. Discuss each behavior with the client and set realistic goals together. Document if the goal was completed and re-establish goals where additional support is needed. *Refer to this sheet to routinely establish new goals and to monitor the progress of goals that have already been established.* A transition should be considered when the adolescent has accomplished all tasks within the plan.

Comprehensive transition checklist	Expected age range of accomplish-ment (Years of age)*	Discussed (√)	Goal for completion (month and year)	Goal completed? (Y/N)	If goal not completed, new goal date (month and year)	Goal completed? (Y/N)	Notes
Interact directly with the health care team and ask questions.	Below 11						
Explain knowledge surrounding HIV.	Below 11						
Identify symptoms of grief, and has identified person who they can speak with when grieving.	Below 11						
Describe stigma and its ill effects.	Below 11						
Current with immunizations and health screenings.	Below 11						
Engage in positive living behaviors (nutrition, exercise).	Below 11						
Able to explain what HIV is.	11–14						
Able to explain what CD4 cells are.	11–14						
Able to explain what viral load is.	11–14						
Verbalize the names and dosages of medications.	11–14						

Comprehensive transition checklist	Expected age range of accomplish-ment (Years of age)*	Discussed (√)	Goal for completion (month and year)	Goal completed? (Y/N)	If goal not completed, new goal date (month and year)	Goal completed? (Y/N)	Notes
Verbalize rules for taking medications (with food, etc.).	11–14						
Discuss pros/cons of contraception options.	11–14						
Explain sexually transmitted infections, including transmission and prevention.	11–14						
Explain implications of HIV diagnosis on pregnancy.	11–14						
Abstain from drugs that have not been prescribed, such as alcohol and ciga-rettes, and is aware of risk reduction behaviors.	11–14						
Independently gives medical history.	11–14						
Explain reasons for disclosure and various disclosure methods.	11–14						
Attend first peer support group.	11–14						
Verbalize pos-sible side effects of medications.	15–24						
Verbalize when and how to call a doctor.	15–24						
Verbalize when and how to access urgent/emergency care.	15–24						
Identify members of the health care team, their roles, and how to con-tact them.	15–24						

Comprehensive transition checklist	Expected age range of accomplish-ment (Years of age)*	Discussed (√)	Goal for completion (month and year)	Goal completed? (Y/N)	If goal not completed, new goal date (month and year)	Goal completed? (Y/N)	Notes
Verbalize knowl-edge surrounding other available community ser-vices for ALHIV and access them independently.	15–24						
Fill prescriptions and obtain refills independently.	15–24						
Take medication independently and is adherent to medications.	15–24						
Independently makes appointments.	15–24						
Independently sets up transportation for appointments.	15–24						
Keeps a calendar of appointments and routinely attends appointments.	15–24						

Adapted from Bartlett et al. 2011.

* Expected ages may be different dependent on your setting, culture, and the client's cognitive and behavioral development. Adapt accordingly.

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