

Adolescents and Young Adults with HIV

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Key Considerations and Recommendations
<ul style="list-style-type: none">Adolescents and young adults (AYA) with HIV largely belong to two distinct groups: those who acquired HIV in the first decade of life and who may be heavily antiretroviral therapy (ART)–experienced (early-acquired HIV); and those who acquired HIV in or after the second decade of life who may be mostly ART-naive.ART is recommended for all AYA with HIV (A1) to reduce HIV-related morbidity, mortality, and transmission.For AYA with HIV who are at risk for poor clinical outcomes, it is critically important to assess the behavioral and psychosocial context, and their ability to adhere to ART. Efforts should be made to provide youth-friendly support and infrastructure to reduce barriers to adherence and maximize success in achieving sustained viral suppression (AIII).Pediatric and adolescent care providers should prepare AYA with HIV for the transition into adult care settings. Adult providers should be knowledgeable about this unique patient population and the challenges that frequently accompany the transition into the adult care setting. Consulting and collaborating with pediatric and adolescent HIV care providers is critical to ensure the successful transition of AYA with HIV to adult providers and continued engagement in care (AIII).
<p>Rating of Recommendations: A = Strong; B = Moderate; C = Optional</p> <p>Rating of Evidence: I = Data from randomized controlled trials; II = Data from well-designed nonrandomized trials or observational cohort studies with long-term clinical outcomes; III = Expert opinion</p>

Introduction

Adolescents (13–19 years old) and young adults (20–24 years old) (AYA) with HIV consistently account for about one-fifth of new infections in the United States.¹ AYA with HIV have lower rates of testing, diagnosis, treatment engagement, and viral suppression than adults with HIV. Importantly, unique developmental, psychosocial, behavioral, and infrastructural factors affect this vulnerable population. Without having their specific challenges and needs addressed, AYA with HIV remain at risk for poorer HIV-related outcomes, including persistent viremia, drug resistance, morbidity, mortality, and secondary transmission.

Epidemiology

Globally, approximately 5 million young people aged 15 to 25 years live with HIV.² AYA with HIV are mostly individuals who acquired HIV in the first decade of life, mainly perinatally and rarely via blood transfusion or from sexual abuse. During adolescence and young adulthood, most individuals acquire HIV through sexual activity. Among the latter group, the Centers for Disease Control and Prevention (CDC) estimates that consistently one-fifth of the approximately 40,000 individuals newly diagnosed with HIV in the United States annually are adolescents and young adults.¹ The majority of new infections in this age group are among Black/African Americans and Hispanic/Latino males who identify as men who have sex with men (MSM). For example, in 2018, more than 50% of the infections in this age group were among young Blacks and African Americans, and 27% were among Hispanics and Latinos. Most (87%) were male, with 92% identifying as MSM. Compared to adults with HIV, AYA with HIV are less likely to have acquired HIV from injection drug use, and trends in HIV and AIDS prevalence indicate that the disproportionate burden of HIV among racial and ethnic minorities is even greater among youths 13 to 24 years of age than among those older than 24. Together, AYAWH account for approximately 34,000 of the individuals being followed at pediatric and adult clinics in the United States.³

Heterogeneity of Adolescents and Young Adults with HIV

AYA with HIV represent a diverse population in terms of socio-demographics, mode of HIV acquisition, sexual and substance use history, clinical and immunologic status, psychosocial development, and ability to adhere to

medications. These distinctions have implications for HIV treatment, including the best ways to support AYA with HIV to optimize outcomes. AYA with HIV largely belong to two distinct groups:

- ***Adolescents and Young Adults with Early-Acquired HIV:*** These individuals, who acquired HIV in the first decade of life, are more likely to be treatment-experienced and have antiretroviral (ARV) drug resistance that may limit their options for ART regimens. This may be even more relevant for AYA with HIV who emigrated from parts of the world where routine viral load and genotypic resistance testing are not as readily available so that recognition of virologic failure and drug resistance may be delayed or missed. Also, individuals in this group generally have undergone a longer duration of disease chronicity and may have greater disease burden and more complications, less functional autonomy, and higher mortality risks.⁴
- ***Adolescents and Young Adults with HIV Acquired Later in Life:*** Individuals in this group are a more heterogeneous group of mostly young men (especially MSM) and young cisgender and transgender women with HIV acquired primarily through sexual activities. A minority in this group have acquired HIV through injecting drugs or were victims of sexual abuse. The intersection of adolescence and young adulthood with other key risk populations (e.g., MSM, people who use drugs, transgender individuals) magnifies the risk of poor clinical outcomes in this younger population. A statistically higher percentage of individuals in this group reported experiencing an even more extensive number of negative life experiences compared to those who acquired HIV early in life (38.8% versus 16.3%, $P < .012$).⁵

Unique Characteristics and Considerations for Adolescents and Young Adults with HIV

Although a diverse group, many AYA with HIV share unique characteristics that distinguish them from adults with HIV. Furthermore, AYA with HIV have certain commonalities that, while not necessarily unique to youth, disproportionately affect their chances of successful HIV treatment. Compared to adults 25 years old and older, AYA with HIV have poorer outcomes on each step of the HIV care continuum⁶ (i.e., HIV diagnosis, linkage to HIV care, receipt of care, retention in care, achievement of viral suppression, maintenance of viral suppression). Most notably, only 40% of AYA with HIV are aware of their diagnosis and only 6% to 30% are virally suppressed.⁷ These numbers are significantly worse than documented in older adults with HIV.⁸ In one study of MSM of all ages, the percentage of those linked to HIV care within one month of diagnosis was lowest among AYA with HIV aged 13 to 19 (69%) and 20 to 24 (70%) years.⁹ This group also had the lowest rates of retention in care and viral suppression. Older young adults (through age 29), who currently have the highest incidence of HIV infection among all age groups, have similar challenges, with 30% unaware of their infection status. They, too, require focused attention.

There are myriad reasons AYA with HIV do not perform as well on the HIV care continuum and are at greater risk of poorer clinical outcomes than adults with HIV. Perhaps most important, AYA with HIV often do not have the same developmental capacity or ability to secure resources as their adult counterparts. These key features, discussed below, should be considered carefully because they can negatively affect HIV treatment and may alter clinical decision-making.

Adolescents and Young Adults with HIV as a Developmentally Distinct Patient Population

Developmental maturity in AYA with HIV generally can be grouped into several, often overlapping, areas, including physical, cognitive, communication and language, and social and emotional, combined with an emerging recognition of sexual identity. Several overarching factors—especially HIV-related stigma, discrimination, and a fear of familial and/or social rejection—can contribute to impaired development in all areas and adversely affect HIV treatment and clinical outcomes for many AYA with HIV. Additional important psychosocial factors discussed below commonly are seen in this population and also can affect development and successful HIV treatment.

Key developmental factors that may impact HIV treatment are highlighted below:

- **Cognitive development:** Evolving cognitive processes, which normally continue well into the third decade of life, are particularly relevant to HIV treatment in AYA with HIV. Their developing decision-making capacity often is driven by concrete thinking processes, risk-taking behaviors, preoccupation with self-image, and the need to fit in with their peers, all of which can affect HIV treatment negatively, including medication adherence and long-term clinical outcomes.^{4, 10, 11} Likewise, AYA with HIV are at risk for neurocognitive impairment and mental health comorbidities,¹²⁻¹⁵ including psychiatric, behavioral, and substance use disorders, which can further affect cognitive development and compromise effective HIV treatment.
- **Physical development:** The rapid physiologic changes (e.g., puberty, rapid growth) that occur in adolescence may result in altered ARV pharmacokinetics, underscoring the importance of adolescent-specific studies.⁴ AYA with HIV, particularly those with infection acquired early in life and/or while sexually immature, also are at risk for impaired physical development, especially delayed sexual maturation and impaired normal bone development, which may have long-term consequences like reduced final height and peak bone mass, the latter being a key risk factor for developing osteoporosis.¹⁶ Both delayed maturation and short stature may increase anxiety, depression, and stigma, which may, in turn, affect treatment adherence.¹⁷ AYA with HIV who acquire HIV later in life still may be affected because peak bone mass is not achieved until around age 30. A small study showed lower bone mass in Tanner Stage 5 young men aged 20 to 25 years who acquired HIV during adolescence than in HIV-uninfected age-matched controls.¹⁸

Thus, developmental maturity should be considered in AYA with HIV, because associated clinical implications may alter HIV treatment decisions, including ARV selection and dosing.

Psychosocial and Related Risk Factors Affecting Adolescents and Young Adults with HIV

Several psychosocial, behavioral, and environmental risk factors affect many AYA with HIV and can undermine successful HIV treatment disproportionately in this population. Common key risk factors are summarized here:

- **Mental and behavioral health:** The percentage of AYA with HIV with behavioral and mental health conditions is very high and can undermine engagement in care and medication adherence. The most common conditions include anxiety and behavioral disorders, mood disorders (including depression), and attention deficit hyperactivity disorder. Among adolescents with early-acquired HIV, nearly 70% meet criteria for a psychiatric disorder at some point in their lives.^{13, 19-21} Similarly, depression and anxiety were identified by symptom inventory 43% and 31% of the time, respectively, among AYA with HIV presenting for care at treatment sites in the Adolescent Trials Network.²²
- **Substance use:** Substance use is prevalent among AYA with HIV. Among more than 2,000 AYA with HIV (72% acquiring HIV later in life) surveyed by the Adolescent Trials Network, weekly or more frequent use of tobacco (33%), marijuana (28%), alcohol (21%), and other illicit drugs (23%) was reported.^{23, 24} Young MSM had higher odds of each substance use behavior, whereas transgender women had increased odds of marijuana and other illicit drugs. Suboptimal ART was associated with increased risk of substance use behaviors,²⁴ underscoring the need to screen for and address substance use improve treatment outcomes.
- **Transgender AYA with HIV:** About 1 in 3 new HIV diagnoses among transgender individuals are among those aged 13 to 24 years.^{25, 26} Transgender AYA with HIV report high rates of stigma and other structural and logistical barriers that affect their access to gender-affirming care, as well as HIV prevention and treatment services, which are known to be associated with retention in care and adherence to treatment (see [Transgender People with HIV](#)).

- **Homelessness and unstable housing:** Among the 4.2 million homeless adolescents and young adults in the United States (of whom 700,000 are unaccompanied minors),²⁷ the estimated HIV prevalence ranges from 3% to 16%. Youth who identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ); those with mental health concerns; and those who engage in substance use are disproportionately represented among homeless youth.²⁸ Homeless and unstably housed AYA with HIV have greater difficulties securing and sustaining resources and engaging in and being retained in care and treatment.²⁹
- **Additional social and environmental factors:** A number of social and environmental factors commonly found among AYA with HIV negatively affect their HIV treatment, including limited familial and/or social support, lack of health insurance and/or experience with health care systems, unstructured and chaotic lifestyles, transportation barriers, food insecurity, limited educational opportunities, limited employment opportunities and/or unstable employment, and a history of trauma and/or sexual abuse.³⁰

Optimizing Treatment Effectiveness and Supporting Adherence in Adolescents and Young Adults with HIV

Given the unique physiologic, developmental, and psychosocial characteristics discussed above, AYA with HIV require comprehensive systems of care with culturally competent providers and tailored treatment to serve all their specific medical and psychosocial needs. To maximize their chances of success, it is also imperative to routinely assess each AYA with HIV for individual factors that may need to be addressed or considered in treatment decisions or that may affect adherence.

Table 15 summarizes common adherence barriers among AYA with HIV, along with recommended support strategies. Refer to the [Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection](#) and the [Adherence to Antiretroviral Therapy in Children and Adolescents with HIV](#) additional approaches. Targeted interventions to improve treatment effectiveness and adherence related to a few key psychosocial factors among AYA with HIV also are highlighted here:

- **Mental health care:** Strategies to improve the provision of mental health care for AYA with HIV are critically important for optimizing treatment for co-occurring HIV and mental health problems.³¹ These strategies include improving provider education, integrating trauma-informed care practices, increasing access to mental health professionals through colocated services for HIV care, expanding care delivery paradigms like telemedicine, and optimizing treatment approaches. An example of the latter is a combination of tailored psychotherapy and pharmacotherapy.^{26, 32} Further guidance for providing appropriate mental health care for AYA with HIV can be found in the [Pediatric Guidelines](#).
- **Substance use disorders:** Providers should assess and recommend treatment for substance use disorders, with consideration of emerging substance use trends, such as the use of electronic vapor products. Further guidance for providing appropriate substance use screening and treatment for AYA with HIV can be found in the [Pediatric Guidelines](#) and in the [Substance Use Disorders and HIV](#) section.
- **Transgender AYA with HIV:** Providers must increase their understanding of this population to minimize barriers and optimize testing, engagement, and outcomes for transgender AYA with HIV. Drug-drug interactions between hormonal therapy and ART can occur but are less common with newer ART regimens. Further information can be found in the [Transgender People with HIV](#) section and [Adolescent Trials Network Transgender Youth Resources](#).³³
- **Psychosocial and environmental stressors:** Multimodal interventions that enhance social support and teach adaptive coping skills may help AYA with HIV manage environmental stressors and improve clinical outcomes.

Specific Antiretroviral Therapy Considerations in Adolescents and Young Adults with HIV

All AYA with HIV should initiate ART as soon as possible and stay on ART indefinitely to maximize viral suppression, reduce morbidity and mortality, and prevent secondary HIV transmission (**AI**). As described below, clinicians should consider simplifying ART regimens and using antiretrovirals with high barriers to resistance whenever possible to support adherence.

Strategies to Improve Medication Adherence

Clinicians selecting ART for AYA with HIV must balance the goal of prescribing a maximally potent regimen with a patient-by-patient assessment of existing and potential adherence barriers and available youth-friendly support strategies to facilitate adherence.³⁴ Additional considerations and strategies that may affect adherence among AYA with HIV are highlighted below in **Table 13**:

Table 13 Antiretroviral Therapy-Specific Strategies to Improve Medication Adherence	
Regimen selection	<ul style="list-style-type: none">• Simple ART regimens (e.g., fixed-dose, once daily combinations) with high barriers to resistance are preferable, if possible.³⁵• Minimal side effects (e.g., gastrointestinal)
Treatment plan	<ul style="list-style-type: none">• Develop the plan in partnership with AYA with HIV, considering daily schedule; tolerance of pill number, size, and frequency; issues affecting absorption; and potential adverse effects and interactions with other medications.^{34,36}• Design adolescent-friendly reminder systems³⁷ (e.g., apps, cell phone reminders, pill boxes) for adherence support.³⁸
Motivators	<ul style="list-style-type: none">• Emphasize personal benefits (e.g., viral suppression, improved health).• Undetectable equals untransmittable (U=U) status disclosure to sexual partners without HIV may act as a particularly strong motivator for reducing stigma and improving adherence among AYA with HIV.

Antiretroviral Therapy Regimens for Adolescents and Young Adults with HIV Without Drug Resistance

The boosted protease inhibitor (PI) darunavir (DRV) and the integrase strand transfer inhibitors (INSTIs) dolutegravir (DTG) and bictegravir (BIC) offer once-daily dosing. When coformulated with a dual nucleoside backbone, they also provide single-tablet regimens with high genetic barriers to resistance.

Clinical trials have demonstrated the superiority of DTG over boosted PI-based regimens. BIC coformulated with tenofovir (TAF) and emtricitabine (FTC) also appears to have a low risk of treatment-emergent resistance and is available as a single-tablet regimen with a small pill size and no food requirements. BIC is currently licensed for use in children or adolescents ≥ 25 kg. Adolescent studies are ongoing with an adult fixed-dose combination of BIC/FTC/TAF from 12 years of age and 35 kg with a favorable interim analysis in a stable adolescent switch study.³⁹

A two-drug once-daily single-tablet regimen of DTG/lamivudine is recommended as an initial ART regimen except for individuals with HIV RNA $>500,000$ copies/mL, hepatitis B virus (HBV) coinfection, or in whom ART is to be started before the results of HIV genotypic resistance testing for reverse transcriptase or HBV testing are available.

Long-acting formulation regimens, the first of which (cabotegravir/rilpivirine) was recently FDA-approved in the United States, are considered a viable option for patients who are engaged in care, virologically suppressed on oral therapy, and agreeable to the administration schedule. These agents are being studied for AYA with HIV⁴⁰ ages 12 to 17 without relevant antiretroviral drug resistance. Case reports of viral suppression with the use of long-acting rilpivirine (RPV) and cabotegravir (CAB)⁴¹ in AYA with HIV with a history of poor adherence are encouraging (see [Optimizing Antiretroviral Therapy in the Setting of Virologic Suppression](#)). Studies to evaluate these modalities among nonadherent AYA with HIV are under development.⁴²

Antiretroviral Therapy—Experienced Adolescents and Young Adults with HIV with Drug Resistance

AYA with HIV who acquired HIV early in life often have treatment challenges associated with the long-term use of ART that mirrors those of ART-experienced adults, such as extensive resistance, complex regimens, and adverse drug effects. In ART-experienced adolescents, DTG was safe and well tolerated, and it achieved viral suppression rates of 44% to 66% when combined with an optimized background regimen. Acquired treatment-emergent INSTI resistance may occur.⁴³ For adolescents with dual-class resistance, the introduction of DRV/cobicistat/FTC/TAF in combination with DTG offers the potential of a potent triple-class regimen with a high genetic barrier to resistance with only two pills once daily⁴⁴ (see [Virologic Failure](#) and [Optimizing Antiretroviral Therapy in the Setting of Virologic Suppression](#)).

Antiretroviral Therapy Considerations in Sexually Immature Adolescents and Young Adults with HIV

The physiologic changes (e.g., puberty, rapid growth) that occur in adolescence may result in altered pharmacokinetics. Therefore, although generally it is appropriate for postpubertal adolescents to be dosed with ARV drugs according to adult guidelines, adolescents in early puberty should be dosed according to the [Pediatric Guidelines](#), which factor in dosages by weight and sexual maturity ratings.

Additional Antiretroviral Therapy Considerations in Adolescents and Young Adults with HIV

Additional considerations include an increased risk of side effects, such as bone and renal toxicity with tenofovir-based drugs in the rapidly growing adolescent. These concerns are magnified in low-weight adolescents for whom appropriate lower-dose formulations are not available. Because AYA with HIV have not yet reached peak bone mass, TAF generally should be used instead of TDF, because of a greater bone loss with the latter ARV.

For a more detailed discussion on ART therapy in AYA with HIV, please see the [What to Start](#) section and the [Pediatric Guidelines](#). For additional information on treatment adherence in AYA with HIV, please see [Table 22, Adherence to the Continuum of Care](#), and the [Pediatric Guidelines](#).

Preventive Measures and Supporting Long-Term Health in Adolescents and Young Adults with HIV

People with HIV are at an increased risk of HIV- and ART-related comorbidities, including cardiovascular disease, diabetes, metabolic syndrome, osteoporosis, and neurocognitive impairment. When HIV is acquired at birth or early in life, an individual can live for many decades with the condition. However, engagement in health-risk behaviors (e.g., tobacco smoking, alcohol and drug use, unhealthy diet, physical inactivity) may have greater long-term implications for clinical outcomes in this population.

Preventive health care and promotion of positive health behavior during the critical time of adolescence and young adulthood can shape future habits and clinical outcomes over a lifetime. Incorporating regular screening, preventive health care, and health education is critical for optimizing short- and long-term physical and mental well-being and should be considered part of routine HIV treatment. Careful attention should be paid to modifiable risk factors in these early decades, such as weight gain and obesity, dyslipidemia, vitamin D deficiency, and tobacco use. Aggressive screening and risk factor mitigation early in the life of AYA with HIV not only improves current health but also can decrease their risk of developing comorbidities later in life. See [HIV Medicine Association of the Infectious Diseases Society of America HIV primary care guidance](#) for more details.

Transitioning to Adult HIV Care

Given lifelong infection with HIV and the need for treatment throughout the life course, HIV care programs and

providers need flexibility to transition care appropriately for AYA with HIV. A successful transition requires an awareness of fundamental differences between many adolescent and adult HIV care models.

In most adolescent HIV clinics, care is more teen-centered and multidisciplinary, with primary care highly integrated into HIV care.⁴⁵ Often there is anonymity, with clinics not being devoted specifically to HIV or infectious diseases. Moreover, such services as sexual and reproductive health and mental health care are often found in one clinic setting (i.e., the medical home). Additionally, these clinics are more likely to be “youth-friendly” by including such aspects as waiting areas where AYA with HIV can access computers and other items that may facilitate engagement; flexible schedules that include evening hours or walk-ins; technology like social media and texting to engage patients; staff who are trained specifically in the unique cognitive, developmental, and other psychosocial aspects of AYA with HIV; and lower patient-to-provider ratios. In contrast, some adult HIV clinics may be more HIV-specific and rely more on referral of the patient to separate subspecialty care settings, such as gynecology.⁴⁶ Furthermore, adult clinic settings tend to be larger and can easily intimidate younger, less motivated patients.

Transitioning the care of an AYA with HIV must consider such factors as medical insurance; degree of independence, autonomy, and decision-making capacity; patient confidentiality; and informed consent. Nonetheless, given the structural limitations (adolescent clinics not being able to see patients over a certain age), care transitions must occur, usually between the ages of 21 and 25. The period of transition is a highly vulnerable time for attrition from HIV care. Data on transition outcomes are emerging, showing variable rates of successful transition to adult care ranging between 50% and 85%.⁴⁷⁻⁵⁰

It is important to recognize that the transition for AYA with HIV with early-acquired HIV versus those who acquired HIV later in life may pose distinct challenges. AYA with HIV who acquired HIV early in life—who often have experienced significant instability and prior loss—may experience the transition to adult HIV care as yet another traumatizing event. Alternatively, those who acquired HIV later in life, given their more recent engagement in the medical system, may be less likely to be effectively engaged in pediatric and adolescent care, which may affect their ability to transition successfully. Factors to date that have been associated with successful transition for those with early-acquired HIV include high self-management and perceived emotional and social support.⁵¹

To maximize the likelihood of a successful transition, interventions to facilitate transition are best implemented early on.^{49, 52-54} Strategies and approaches for both the adult and pediatric and adolescent programs are discussed below:

Table 14: Approaches to Optimize Care Transition for AYA with HIV	
Pediatric/Adolescent	Adult
Personnel	
<ul style="list-style-type: none"> Engage a multidisciplinary team knowledgeable about medical and psychosocial issues of AYA with HIV, including the challenges of transitioning youth to adult care settings. Utilize combined internal medicine and pediatrics-trained providers if available. Assign a transition point person and have their contact information readily available. Educate HIV care teams and staff about transitioning AYA with HIV and their needs. 	<ul style="list-style-type: none"> Engage a multidisciplinary adult care team knowledgeable about medical and psychosocial issues of AYA with HIV, including the challenges of transitioning youth to adult care settings. Utilize combined internal medicine and pediatrics providers if available. Assign a transition point person and have their contact information readily available. Identify outreach specialists, navigators, social workers, case managers, and providers with a youth-friendly approach. Educate clinic personnel about AYA with HIV and their challenges to enhance sensitivity and understanding and minimize stigma.

Education and Preparation of AYA with HIV	
<ul style="list-style-type: none"> • Enhance AYA with HIV health literacy, including understanding of HIV and their medical history. • Address patient and family resistance to transition of care caused by lack of information, concerns about stigma or risk of disclosure, and differences in practice styles. • Help youth develop life skills, including, but not limited to, counseling on appropriate use of a primary care provider and how to manage appointments; the importance of prompt symptom recognition and reporting; and self-efficacy in managing medications, insurance, and assistance benefits. 	<ul style="list-style-type: none"> • Meet AYA with HIV before transition, if possible. • Clearly outline policies and expectations before and during the first visit. • Have an orientation plan to acquaint newly transitioned AYA with HIV to the clinic environment and adult clinical care program. • Implement interventions that may improve outcomes, such as patient navigators, peer support groups, mental health assessment, and inclusion of parents and guardians where available. • Address health literacy and ensure AYA with HIV understand HIV, goals of care, etc. • Continue to work with AYA with HIV toward developing life skills, etc.
Strategies and Approaches	
<ul style="list-style-type: none"> • Identify adult care providers able to provide youth-friendly care for adolescents and young adults. • Develop a formal, purposeful individualized transition plan to address comprehensive care needs, including medical, psychosocial, and financial aspects of transitioning to adult HIV care. • Optimize provider communication between adolescent and adult clinics, including a warm multidisciplinary, comprehensive medical history hand-off that includes prior regimens and outcomes (e.g., adherence, virologic failure and resistance). 	<ul style="list-style-type: none"> • Develop a realistic clinic model based on specific needs (e.g., simultaneous transition of mental health and/or case management versus a gradual phase-in) and staffing. • Engage in a warm handoff from the pediatric team, which allows the accepting adult team to learn about and understand the multidisciplinary challenges and goals for the patient. Devise a plan for how to continue building the skills on the adult side. • Build in flexibility (e.g., permissive grace period for appointments, leniency for missed appointments, particularly when first transitioning). • Incorporate other aspects of care beyond HIV management, if possible (e.g., family planning, sexually transmitted infection testing and treatment, mental health, substance use).
Communication	
<ul style="list-style-type: none"> • Foster regular dialogue between pediatric and adolescent and adult teams before and after transition through regular meetings, case conferences, etc. • Solicit feedback from the AYA with HIV. • Use technology (e.g., texting, HIPAA-compliant messaging apps, telemedicine). 	
Evaluation	
<ul style="list-style-type: none"> • Implement ongoing evaluation to measure the success of the selected model (retention in adult care). 	

Discussions regarding transition should begin early and before the actual transition process.⁵⁵ Attention to the key interventions noted above will be likely to improve adherence to appointments and avoid the potential for youth to fall through the cracks, as this concept is referred to commonly in adolescent medicine. For a more detailed discussion on specific topics related to transitioning care for adolescents and young adults, see *Transitioning into Adult HIV Care*. Please also refer to the [Pediatric Guidelines](#).

Table 15: AYA with HIV ARV Adherence Barriers and Strategies to Support Adherence		
ART Adherence Barrier	Adherence Support Strategy	Rationale for Adherence Support Strategy
Prioritization of short-term goals and socialization with peers over daily HIV treatment adherence	Youth-friendly reminder systems (e.g., text, phone, apps)	<ul style="list-style-type: none"> • Daily adherence to ARV regimens may not take priority in the lives of AYA with HIV. • AYA with HIV benefit from reminder systems to facilitate adherence.
	Novel ART delivery strategies (e.g., long-acting oral or injectable ARVs)	<ul style="list-style-type: none"> • AYA with HIV show interest in long-acting alternatives for ART delivery. • Long-acting ARVs are a promising tool to facilitate adherence, once approved for AYA with HIV.
Social concerns related to loss of confidentiality	Simple ARV regimens	<ul style="list-style-type: none"> • Adolescents do not want to be different from peers; adherence to complex regimens is particularly challenging. • Simple ARV regimens are preferable for AYA with HIV.
	User-friendly and discreet regimens	<ul style="list-style-type: none"> • Avoidance of HIV-related stigma and of unintentional disclosure of HIV status is a priority for AYA with HIV. • Protect confidentiality with user-friendly and discreet adherence supports (e.g., discreet pill bottles, reminder systems, etc.).
Side effects/fear of side effects	ARV regimens that minimize side effects	<ul style="list-style-type: none"> • Side effects are associated with nonadherence to ARVs. • Regimens with minimal side effects and medications that manage side effects have utility for AYA with HIV.
Denial or dismissal of HIV diagnosis	Motivational interviewing (MI) and motivational enhancement therapy (MET)	<ul style="list-style-type: none"> • MI and MET acknowledge AYA with HIV's autonomy and potential ambivalence about treatment adherence. • MI and MET have shown promise for improving adherence to chronic disease treatment, including HIV.
	Positive affirmation messages (e.g., text, app)	<ul style="list-style-type: none"> • Electronically delivered positive affirmation messages can improve self-esteem and ARV adherence among AYA with HIV.
Lack of health literacy regarding the benefits of ART	Health literacy support and U=U education	<ul style="list-style-type: none"> • AYA with HIV may not fully understand the importance of taking ARVs daily, particularly when they are asymptomatic. • Increased health literacy is associated with better adherence to ARV regimens. • U=U education holds promise for AYA with HIV.
Mistrust of providers and the medical establishment	Empathetic and patient-centered communication	<ul style="list-style-type: none"> • Communication exploring the needs of AYA with HIV patients can build trust, including exploring needs not directly related to HIV treatment (e.g., school, employment, relationships, etc.).
Mental health and/or substance use	Individualized mental health and substance use services	<ul style="list-style-type: none"> • Comprehensive mental health and substance use services have shown promise for improving viral suppression among AYA with HIV. • Service should be delivered based on individualized needs assessments.
	Directly observed therapy may be considered	<ul style="list-style-type: none"> • For some AYA with HIV with difficult adherence problems, directly observed therapy may be considered.

Table 15: AYA with HIV ARV Adherence Barriers and Strategies to Support Adherence, *continued*

ART Adherence Barrier	Adherence Support Strategy	Rationale for Adherence Support Strategy
Lack of familial and social support	Family and peer support groups	<ul style="list-style-type: none"> • Family members and peers are a defense against stigma and social isolation, source of emotional support, and partners in medication management. • Family and peer support groups have utility for AYA with HIV living with HIV.
Provider views of AYA with HIV as “risky” and/or not ready for ART	Promote development of a positive rather than risk-centered identity among AYA with HIV	<ul style="list-style-type: none"> • Adolescence and young adulthood are periods of identity development where HIV stigma is particularly problematic. • Providers should not conceptualize AYA with HIV as “high risk” to reduce stigma and improve ARV adherence.
Provider implicit biases of AYA with HIV	Implicit bias training	<ul style="list-style-type: none"> • Consciously changing biased associations and repeated bias self-regulation training can reduce providers’ implicit biases.
	Gender-affirming care	<ul style="list-style-type: none"> • Transgender individuals are more likely to achieve viral suppression when HIV care providers affirm their gender (e.g., use chosen name and pronoun). • For a more detailed discussion, see guidelines for Transgender People with HIV.
Lack of youth-friendly services	Dedicated youth HIV clinic	<ul style="list-style-type: none"> • Clinic days or hours dedicated to AYA with HIV patients better address unique adherence needs; youth-friendly services include the following: <ul style="list-style-type: none"> ○ flexible hours, easy scheduling, telephone/telehealth appointments; ○ providers trained in working with AYA with HIV; ○ youth-friendly waiting rooms and physical spaces; ○ supplemental services that comprehensively address psychosocial and health needs of AYA with HIV; and ○ incentives for AYA with HIV care engagement.
	Youth-friendly hours, staff, and physical space	<ul style="list-style-type: none"> • Where dedicated hours and services are not possible, youth-friendly service elements can be integrated into existing clinic structures, e.g.: <ul style="list-style-type: none"> ○ offering evening hours; ○ staff training on service delivery to AYA with HIV; and ○ youth-friendly waiting rooms and physical spaces.
	Referrals to more youth-friendly HIV providers	<ul style="list-style-type: none"> • Where youth-friendly services are not possible, referrals to more youth-friendly HIV care providers should be considered. • Referral decisions should be made collaboratively with the patient.

Table 15: AYA with HIV ARV Adherence Barriers and Strategies to Support Adherence, *continued*

Lack of comprehensive services that address common psychosocial stressors	Supplemental health, behavioral health, and psychosocial support services	<ul style="list-style-type: none"> • Individualized delivery of comprehensive supplemental services helps address unique needs of AYA with HIV, including the following: <ul style="list-style-type: none"> ○ primary care and sexual and reproductive health services; ○ behavioral health services; and ○ psychosocial support services (e.g., school support, transportation, support groups, housing and food assistance).
	Collaboration with and referrals to outside support services	<ul style="list-style-type: none"> • Where delivery of comprehensive supplemental services is not possible, collaborations with and referrals to outside support services should be considered.

Key: ART = antiretroviral treatment; ARV = antiretroviral; AYA = adolescent and young adult; U=U = undetectable equals untransmittable

References

1. Centers for Disease Control and Prevention. HIV and Youth. 2020. Available at: <https://www.cdc.gov/hiv/group/age/youth/index.html>.
2. World Health Organization. HIV and Youth. 2021. Available at: https://www.who.int/maternal_child_adolescent/topics/adolescence/hiv/en/.
3. Centers for Disease Control and Prevention. Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data— United States and 6 U.S. Dependent Areas— 2010. 2012. Available at: https://www.cdc.gov/hiv/pdf/statistics_2010_HIV_Surveillance_Report_vol_17_no_3.pdf.
4. Agwu AL, Fairlie L. Antiretroviral treatment, management challenges and outcomes in perinatally HIV-infected adolescents. *J Int AIDS Soc*. 2013;16:18579. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/23782477>.
5. Lewis JV, Abramowitz S, Koenig LJ, Chandwani S, Orban L. Negative life events and depression in adolescents with HIV: a stress and coping analysis. *AIDS Care*. 2015;27(10):1265-1274. Available at: <https://pubmed.ncbi.nlm.nih.gov/26313848/>.
6. Wood SM, Dowshen N, Lowenthal E. Time to Improve the Global Human Immunodeficiency Virus/AIDS Care Continuum for Adolescents: A Generation at Stake. *JAMA Pediatr*. 2015;169(7):619-620. Available at: <https://pubmed.ncbi.nlm.nih.gov/25985061/>.
7. Zandoni BC, Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. 2014;28(3):128-135. Available at: <https://pubmed.ncbi.nlm.nih.gov/24601734/>.
8. Centers for Disease Control and Prevention. HIV and Youth. 2020. Available at: <https://www.cdc.gov/hiv/group/age/youth/index.html>.
9. Singh S, Mitsch A, Wu B. HIV Care Outcomes Among Men Who Have Sex With Men With Diagnosed HIV Infection - United States, 2015. *MMWR Morb Mortal Wkly Rep*. 2017;66(37):969-974. Available at: <https://www.cdc.gov/mmwr/volumes/66/wr/mm6637a2.htm>.
10. The National Academies of Sciences E, and Medicine. The promise of adolescence: realizing opportunity for all youth. Vol. ed.: 2019. Available at <https://pubmed.ncbi.nlm.nih.gov/31449373/>.
11. Reisner MS, Mimiaga MJ, Skeer MM, Perkovich MB, Johnson MC, Safren SA. A review of HIV antiretroviral adherence and intervention studies among HIV–infected youth. *Top HIV Med*. 2009;17(1):14-25. Available at: <https://www.iasusa.org/wp-content/uploads/2009/02/17-1-14.pdf>.
12. Harris LL, Chernoff MC, Nichols SL, et al. Prospective memory in youth with perinatally-acquired HIV infection. *Child Neuropsychol*. 2018;24(7):938-958. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/28782457>.
13. Bucek A, Leu CS, Benson S, et al. Psychiatric Disorders, Antiretroviral Medication Adherence and Viremia in a Cohort of Perinatally HIV-Infected Adolescents and Young Adults. *Pediatr Infect Dis J*. 2018;37(7):673-677. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/29227462>.
14. Mellins CA, Tassiopoulos K, Malee K, et al. Behavioral health risks in perinatally HIV-exposed

- youth: co-occurrence of sexual and drug use behavior, mental health problems, and nonadherence to antiretroviral treatment. *AIDS Patient Care STDS*. 2011;25(7):413-422. Available at: <https://pubmed.ncbi.nlm.nih.gov/21992620/>.
15. Nichols SL, Brummel SS, Smith RA, et al. Executive Functioning in Children and Adolescents With Perinatal HIV Infection. *Pediatr Infect Dis J*. 2015;34(9):969-975. Available at: <https://pubmed.ncbi.nlm.nih.gov/26376309/>.
 16. Bellavia A, Williams PL, DiMeglio LA, et al. Delay in sexual maturation in perinatally HIV-infected youths is mediated by poor growth. *AIDS*. 2017;31(9):1333-1341. Available at: <https://pubmed.ncbi.nlm.nih.gov/28358737/>.
 17. Dwyer AA, Phan-Hug F, Hauschild M, Elowe-Gruau E, Pitteloud N. TRANSITION IN ENDOCRINOLOGY: Hypogonadism in adolescence. *Eur J Endocrinol*. 2015;173(1):R15-24. Available at: <https://pubmed.ncbi.nlm.nih.gov/25653257/>.
 18. Yin MT, Lund E, Shah J, et al. Lower peak bone mass and abnormal trabecular and cortical microarchitecture in young men infected with HIV early in life. *AIDS*. 2014;28(3):345-353. Available at: <https://pubmed.ncbi.nlm.nih.gov/24072196/>.
 19. Mellins CA, Brackis-Cott E, Leu CS, et al. Rates and types of psychiatric disorders in perinatally human immunodeficiency virus-infected youth and seroreverters. *J Child Psychol Psychiatry*. 2009;50(9):1131-1138. Available at: <https://pubmed.ncbi.nlm.nih.gov/19298479/>.
 20. Mellins CA, Malee KM. Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. *J Int AIDS Soc*. 2013;16(1):18593. Available at: <https://pubmed.ncbi.nlm.nih.gov/23782478/>.
 21. Gadow KD, Chernoff M, Williams PL, et al. Co-occurring psychiatric symptoms in children perinatally infected with HIV and peer comparison sample. *J Dev Behav Pediatr*. 2010;31(2):116-128. Available at: <https://pubmed.ncbi.nlm.nih.gov/20110828/>.
 22. Lally MA, van den Berg JJ, Westfall AO, et al. HIV Continuum of Care for Youth in the United States. *J Acquir Immune Defic Syndr*. 2018;77(1):110-117. Available at: <https://pubmed.ncbi.nlm.nih.gov/28991884/>.
 23. Abrams EJ, Mellins CA, Bucek A, et al. Behavioral Health and Adult Milestones in Young Adults With Perinatal HIV Infection or Exposure. *Pediatrics*. 2018;142(3):e20180938. Available at: <https://pubmed.ncbi.nlm.nih.gov/30097528/>.
 24. Gamarel KE, Brown L, Kahler CW, Fernandez MI, Bruce D, Nichols S. Prevalence and correlates of substance use among youth living with HIV in clinical settings. *Drug Alcohol Depend*. 2016;169:11-18. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5140709/>.
 25. Clark H, Babu AS, Wiewel EW, Opoku J, Crepaz N. Diagnosed HIV Infection in Transgender Adults and Adolescents: Results from the National HIV Surveillance System, 2009-2014. *AIDS Behav*. 2017;21(9):2774-2783. Available at: <https://pubmed.ncbi.nlm.nih.gov/28035497/>.
 26. Reisner SL, Jadwin-Cakmak L, White Hughto JM, Martinez M, Salomon L, Harper GW. Characterizing the HIV Prevention and Care Continuum in a Sample of Transgender Youth in the U.S. *AIDS Behav*. 2017;21(12):3312-3327. Available at: <https://pubmed.ncbi.nlm.nih.gov/29138982/>.

27. Beech BM, Myers L, Beech DJ, Kernick NS. Human immunodeficiency syndrome and hepatitis B and C infections among homeless adolescents. *Semin Pediatr Infect Dis*. 2003;14(1):12-19. Available at: <https://pubmed.ncbi.nlm.nih.gov/12748917/>.
28. Van Leeuwen JM, Hopfer C, Hooks S, White R, Petersen J, Pirkopf J. A snapshot of substance abuse among homeless and runaway youth in Denver, Colorado. *J Community Health*. 2004;29(3):217-229. Available at: <https://pubmed.ncbi.nlm.nih.gov/15141897/>.
29. Palepu A, Milloy MJ, Kerr T, Zhang R, Wood E. Homelessness and adherence to antiretroviral therapy among a cohort of HIV-infected injection drug users. *J Urban Health*. 2011;88(3):545-555. Available at: <https://pubmed.ncbi.nlm.nih.gov/21409604/>.
30. Bekker LG, Hosek S. HIV and adolescents: Focus on young key populations. *JIAS: Journal of the International AIDS Society*. 2015;18(Suppl 1):1-94. Available at: <https://doi.org/10.7448/IAS.18.2.20076>.
31. Wisdom JP, Cavaleri M, Gogel L, Nacht M. Barriers and facilitators to adolescent drug treatment: Youth, family, and staff reports. *Addiction Research & Theory*. 2011;19(2):179-188. Available at: <https://www.tandfonline.com/doi/abs/10.3109/16066359.2010.530711>.
32. Brown LK, Kennard BD, Emslie GJ, et al. Effective Treatment of Depressive Disorders in Medical Clinics for Adolescents and Young Adults Living With HIV: A Controlled Trial. *J Acquir Immune Defic Syndr*. 2016;71(1):38-46. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4712723/>.
33. ATN Adolescent Trials Network. Transgender Youth Resources. 2021. Available at: <https://atnonline.org/public/TransYouthRes.asp>.
34. Guilamo-Ramos V, Thimm-Kaiser M, Benzekri A, Futterman D. Shifting the paradigm in HIV prevention and treatment service delivery toward differentiated care for youth. Presented at: NAM Perspectives, Discussion Paper; 2019. Available at: <https://nam.edu/shifting-the-paradigm-in-hiv-prevention-and-treatment-service-delivery-toward-differentiated-care-for-youth/>.
35. Griffith DC, Farmer C, Gebo KA, et al. Uptake and virological outcomes of single- versus multi-tablet antiretroviral regimens among treatment-naïve youth in the HIV Research Network. *HIV Med*. 2019;20(2):169-174. Available at: <https://pubmed.ncbi.nlm.nih.gov/30561888/>.
36. Lyon ME, Trexler C, Akpan-Townsend C, et al. A family group approach to increasing adherence to therapy in HIV-infected youths: results of a pilot project. *AIDS Patient Care STDS*. 2003;17(6):299-308. Available at: <https://pubmed.ncbi.nlm.nih.gov/12880493/>.
37. Belzer ME, Kolmodin MacDonell K, Clark LF, et al. Acceptability and Feasibility of a Cell Phone Support Intervention for Youth Living with HIV with Nonadherence to Antiretroviral Therapy. *AIDS Patient Care STDS*. 2015;29(6):338-345. Available at: <https://pubmed.ncbi.nlm.nih.gov/25928772/>.
38. Garofalo R, Kuhns LM, Hotton A, Johnson A, Muldoon A, Rice D. A Randomized Controlled Trial of Personalized Text Message Reminders to Promote Medication Adherence Among HIV-Positive Adolescents and Young Adults. *AIDS Behav*. 2016;20(5):1049-1059. Available at: <https://pubmed.ncbi.nlm.nih.gov/26362167/>.
39. Gaur A, Cotton M, Rodriguez C, et al. Bictegravir/FTC/TAF single-tablet regimen in adolescents & children: week 48 results. Presented at: Conference on Retroviruses and Opportunistic

- Infections; 2019. Seattle, Washington. Available at: <https://www.croiconference.org/abstract/bictegravirtctaf-single-tablet-regimen-adolescents-children-week-48-results/>.
40. Bolton C, Gaur A, Adeyeye A, et al. IMPAACT 2017 / MOCHA. 2020. Available at: <https://www.impaactnetwork.org/studies/impaact2017>.
 41. Chilton D, Mukela A, Ali A, Doctor J, Kulasegaram R. Long acting (LA), injectable ARVs in clinical practice – Two UK case studies of compassionate access to LA cabotegravir and rilpivirine in young adults with perinatally acquired HIV-1. Presented at: 25th Annual Conference of the British HIV Association (BHIVA); 2019. Bournemouth International Centre, UK. Available at: <https://www.bhiva.org/file/5ca728cf8fae6/P011.pdf>.
 42. International Maternal Pediatric Adolescent AIDS Clinical Trials Network. IMPAACT 2022. 2021. Available at: <https://www.impaactnetwork.org/studies/impaact2022>.
 43. Viani RM, Ruel T, Alvero C, et al. Long-Term Safety and Efficacy of Dolutegravir in Treatment-Experienced Adolescents With Human Immunodeficiency Virus Infection: Results of the IMPAACT P1093 Study. *J Pediatric Infect Dis Soc*. 2020;9(2):159-165. Available at: <https://pubmed.ncbi.nlm.nih.gov/30951600/>.
 44. Pantheon Inc. (2021). Symtuza [package insert]. Available at: <https://www.janssenlabels.com/package-insert/product-monograph/prescribing-information/SYMTUZA-pi.pdf>.
 45. Griffith DC, Agwu AL. Caring for youth living with HIV across the continuum: turning gaps into opportunities. *AIDS Care*. 2017;29(10):1205-1211. Available at: <https://pubmed.ncbi.nlm.nih.gov/28278569/>.
 46. Lee L, Yehia BR, Gaur AH, et al. The Impact of Youth-Friendly Structures of Care on Retention Among HIV-Infected Youth. *AIDS Patient Care STDS*. 2016;30(4):170-177. Available at: <https://pubmed.ncbi.nlm.nih.gov/26983056/>.
 47. Ryscavage P, Macharia T, Patel D, Palmeiro R, Tepper V. Linkage to and retention in care following healthcare transition from pediatric to adult HIV care. *AIDS Care*. 2016;28(5):561-565. Available at: <https://pubmed.ncbi.nlm.nih.gov/26766017/>.
 48. Griffith D, Jin L, Childs J, Posada R, Jao J, Agwu A. Outcomes of a Comprehensive Retention Strategy for Youth With HIV After Transfer to Adult Care in the United States. *Pediatr Infect Dis J*. 2019;38(7):722-726. Available at: <https://pubmed.ncbi.nlm.nih.gov/30985513/>.
 49. Xia Q, Abraham B, Shah D, Ramaswamy C, Braunstein SL, Torian LV. Transition from paediatric to adult care among persons with perinatal HIV infection in New York City, 2006-2015. *Aids*. 2018;32(13):1821-1828. Available at: <https://pubmed.ncbi.nlm.nih.gov/29894382/>.
 50. Maturo D, Powell A, Major-Wilson H, Sanchez K, De Santis JP, Friedman LB. Transitioning Adolescents and Young Adults With HIV Infection to Adult Care: Pilot Testing the “Movin’ Out” Transitioning Protocol. *J Pediatr Nurs*. 2015;30(5):e29-35. Available at: <https://pubmed.ncbi.nlm.nih.gov/26276460/>.
 51. Tassiopoulos K, Huo Y, Patel K, et al. Healthcare Transition Outcomes Among Young Adults With Perinatally Acquired Human Immunodeficiency Virus Infection in the United States. *Clin Infect Dis*. 2020;71(1):133-141. Available at: <https://pubmed.ncbi.nlm.nih.gov/31584617/>.

52. Valenzuela JM, Buchanan CL, Radcliffe J, et al. Transition to adult services among behaviorally infected adolescents with HIV--a qualitative study. *J Pediatr Psychol*. 2011;36(2):134-140. Available at: <https://pubmed.ncbi.nlm.nih.gov/19542198/>.
53. Hussen SA, Chahroudi A, Boylan A, Camacho-Gonzalez AF, Hackett S, Chakraborty R. Transition of youth living with HIV from pediatric to adult-oriented healthcare: a review of the literature. *Future Virol*. 2015;9(10):921-929. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4433446/>.
54. Cervia JS. Easing the transition of HIV-infected adolescents to adult care. *AIDS Patient Care STDS*. 2013;27(12):692-696. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3868277/>.
55. Committee On Pediatric AIDS. Transitioning HIV-infected youth into adult health care. *Pediatrics*. 2013;132(1):192-197. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/23796739>.