

Strategies for Identifying and Linking HIV-Infected Infants, Children, and Adolescents to HIV Care and Treatment



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WHY IS PEDIATRIC CASE FINDING IMPORTANT?

There has been tremendous improvement in the coverage of programs to prevent mother-to-child HIV transmission (PMTCT) over the past decade, especially with the implementation of the Option B+ strategy which supports initiating lifelong ART in pregnant women living with HIV. As a result, the number of new pediatric HIV infections among infants has dropped by 52%—from 550,000 in 2001 to 260,000 in 2012.¹ Despite this progress, an estimated 3.4 million children under the age of 15 years are living with HIV globally.² Treatment coverage for children living with HIV remains unacceptably low with only three in ten eligible children receiving antiretroviral therapy (ART) as of 2012.²

Among infants and children not taking ART, HIV infection is often rapidly progressive and fatal. Approximately 20% of HIV-infected infants will die by 3 months of age without treatment, half will die before reaching their second birthday, and three-fourths will die by 5 years of age.³⁻⁴ ART initiation upon diagnosis can reduce mortality among HIV-infected infants by up to 75%.⁵ Current guidelines by the World Health Organization (WHO) recommend that all HIV-infected children under 5 years of age be initiated on ART at the time of diagnosis regardless of immunologic or clinical staging.⁶

Identifying and diagnosing children as HIV-infected is the first step in the continuum of pediatric care and treatment. Yet despite the availability of life-saving treatment, many HIV-exposed infants and children are never offered an HIV diagnostic test.⁷ Among reporting countries, only one-third of infants born to HIV-infected mothers received an HIV test in 2012, with some countries reporting infant testing rates below 10%.² Children who do receive an HIV test are often tested later than recommended, even though earlier testing is needed in order to facilitate life-saving treatment initiation. Moreover, provider-initiated HIV testing on inpatient wards and in TB and malnutrition clinics to improve management of these children is frequently low but is critical to improve the management of children with these comorbidities. When testing at these sites is evaluated, the yield is high, illustrating the urgent need to expand case finding and treatment access to these children already in contact with healthcare services. Beyond infancy, there are long-term survivors who remain unidentified as HIV-infected throughout childhood and into adolescence, often being missed during routine healthcare encounters. Improved case finding of HIV-infected infants, children, and adolescents through implementation of routine, systematic HIV testing and counseling (HTC) approaches in these settings is urgently needed to maximize pediatric treatment coverage and reduce rates of infant and child mortality attributable to HIV and AIDS.

WHAT STRATEGIES CAN BE USED TO IMPROVE PEDIATRIC CASE FINDING?

Strategies for strengthening pediatric case finding are summarized in Figure 1 below. Programs should prioritize the funding of strategies which yield a positivity rate that is higher than the estimated HIV prevalence among children and adolescents in the district, region, or province where the program is located, and strategies with the lowest cost per case newly identified.

Figure 1. Strategies for Strengthening Case Finding among Infants, Children, and Adolescents

Problem

- Only one third of infants born to HIV-infected mothers received an HIV test in 2012.
- Only three in ten eligible children received antiretroviral therapy in 2012.
- Without treatment, 75% of HIV-infected children will die by their fifth birthday.

Goal

- Test 100% of HIV-exposed infants, children and adolescents.
- Identify all children aged 0–15 years living with HIV and link them to care and treatment.

Testing Strategies

- Strengthen early infant diagnosis (EID) for HIV-exposed infants.
- Test all children of adults receiving any HIV service (PMTCT, Care, ART) through facility or home-based index case testing.
- Test all children and adolescents attending TB clinics, malnutrition services, and/or admitted to the pediatric ward.
- Test all children and adolescents receiving orphan and vulnerable children (OVC) services.
- In high prevalence settings (>5%), test mothers or infants attending immunization or under-5 clinics to identify HIV-exposed infants.

Outcomes

- Improved ART coverage among pediatric and adolescent populations.
- Reduced rates of HIV-related morbidity and mortality among pediatric populations.
- Improved child survival and achievement of an AIDS-free generation.

Strengthen Early Infant Diagnosis for HIV-Exposed Infants

All HIV-exposed infants should receive a virological HIV test by four to six weeks after birth, even if their mothers received ART or ARV prophylaxis during pregnancy.⁶ However, only an estimated 15% of HIV-exposed infants globally receive a virologic test by eight weeks of age.⁹ This is often due to difficulties in collecting, transporting, and processing virologic tests as well as a lack of systems to track mother-baby pairs. Long turnaround times (TATs) between the health facility and laboratory for sample submission and return of test results increase the likelihood that infected infants will die or be lost to follow-up before receiving their test results. To reduce TATs, countries have centralized the PCR testing, established sample transport hubs, and implemented innovative strategies for returning test results to health facilities via email, text messaging, and remote data printing.⁹ Establishing coordinated care for the mother-infant pair has also been shown to increase coverage of HIV DNA PCR testing among HIV-exposed infants.¹⁰

While strengthening early infant diagnosis is a necessary component of improving pediatric case finding, it is insufficient to identify all HIV-exposed and infected infants, children, and adolescents. Some mothers may not come to the facility for antenatal care and may not receive PMTCT services or may receive services late. Many HIV-exposed infants and children are not systematically followed until the end of the breastfeeding period and, as a result, do not receive a definitive diagnosis. Moreover, many older children and adolescents living with HIV are long-term survivors who have not been previously identified as HIV-infected or even as HIV-exposed. Other testing strategies are therefore needed to ensure that 100% of HIV-exposed and infected infants, children, and adolescents receive an HIV test. These strategies are described below.

Test All Children of Adults Receiving Any HIV Service (PMTCT, Care, ART) Through Either Facility or Home-Based Index Case Testing

Testing the children of HIV-infected adults as well as the siblings of HIV-infected children receiving any HIV service (e.g. HIV care and support, ART, PMTCT, and TB-HIV treatment) is an important strategy for improving early case finding for HIV-infected children.^{7,11} Family counseling can also facilitate disclosure and communication within the family and improve adherence and retention in HIV clinical care.⁷ Evidence indicates, however, that few children of people living with HIV have been tested for HIV. In Malawi, only 20% of children of adult ART patients had been tested for HIV,¹² and in Uganda 36% of children born to parents known to be HIV-infected had been tested for HIV prior to hospitalization in the pediatric ward.¹³



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To improve the uptake of family HTC services, health care providers should reinforce the importance of partner and family testing at every clinic visit. In addition, offering testing to the whole family at either the health facility or through home-based index case testing can improve the chance that children with an undiagnosed HIV infection will be identified. For example, the Tingathe Program in Malawi utilizes community health workers to offer home-based HTC services to the partners and family members of patients known to be HIV-infected. This program has led to a 10-fold increase in the identification and enrollment of HIV-infected children into pediatric care and treatment services.¹⁴

Testing the infants and children of key populations groups living with HIV, particularly HIV-infected female sex workers and injection drug users is also an important strategy for improving pediatric case finding among hard-to-reach populations. Given the difficulty in accessing these populations, it is unlikely that these children will be diagnosed through routine health services. Thus, it is important to reach these children through services targeted towards their parents and caregivers. Programs offering HTC and treatment services to key population groups should include counseling about the need to get infants and children tested and offer family testing services either at the specialized clinic or through home-based index case testing.



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Test All Children Attending TB Clinics, Malnutrition Services, and/or Admitted to the Pediatric Ward

Routinely testing all children and adolescents attending clinics where HIV is likely to be an underlying cause of illness is a highly effective strategy to identify HIV-exposed and HIV-infected children who were either missed during the early postnatal period, or who acquired HIV later in infancy via breastfeeding.¹⁷ This includes testing children attending tuberculosis (TB) clinics, malnutrition clinics, or admitted to inpatient pediatric wards.¹¹

In Zambia, for example, 29% of children admitted to an inpatient pediatric ward tested HIV-positive.¹⁸ Similarly, in Uganda, 31% of children admitted to the nutrition ward were found to be HIV-infected. In Malawi, routine HTC offered by lay counselors to children in the pediatric inpatient ward found an 8.5% prevalence rate, double the national 4.8% prevalence rate for children of the same age.¹⁹ Despite this evidence, however, few children are tested in hospitals, representing a significant missed opportunity for identifying HIV-exposed and infected children. In addition, offering an HIV test to the parents and caregivers of children attending hospital-based services can also identify previously undiagnosed cases of HIV and ensure that the entire family receives the services they need to remain healthy.

In lower prevalence or concentrated epidemics with less than 5% adult HIV prevalence, testing every child or adolescent admitted to the pediatric ward may not be a cost-effective approach. However, the WHO recommends that all children or adolescents in low or concentrated epidemics who present at a health facility with signs or symptoms of HIV infection should receive an HIV test. This includes children and adolescents with TB or who are malnourished. In these settings, symptom-based pediatric HIV testing should be offered as part of the medical diagnostic process.⁸

Test Children Receiving Orphan and Vulnerable Children (OVC) Services

Over the past 30 years, an estimated 17 million children have lost one or both parents due to AIDS; 90% of these children live in sub-Saharan Africa.¹⁵ Orphaned children are at high risk for HIV from vertical transmission and, because of their economic vulnerability, may also be at risk from horizontal HIV transmission through sexual abuse or early sexual debut.¹⁵ Integrating HTC services or referrals into OVC programs can help identify orphaned children living with HIV. In Zimbabwe, 18% of orphaned children attending a community-based OVC program tested HIV-positive,¹⁶ emphasizing the need for wider implementation of this strategy to improve pediatric case finding. All children receiving OVC services should have a known HIV status. This includes offering or referring all children receiving OVC services to HTC programs and referring those found to be HIV-infected for HIV care and treatment services.

In High Prevalence Settings (>5% Adult HIV Prevalence), Screen Mothers or Infants Attending Immunization or Under-5 Clinics to Identify HIV-Exposed Infants

While many women in sub-Saharan Africa deliver outside of formal healthcare facilities, most infants routinely attend immunization or under-5 clinics. In high-burden areas, screening mothers or infants attending immunization or under-5 clinics is another important strategy for identifying HIV-exposed and HIV-infected infants.²⁰ In high prevalence settings or areas, an initial rapid test can be used to screen mothers or newborns for HIV infection or exposure, respectively. For infants who test positive or whose mothers are HIV-infected, a subsequent PCR test should be offered. These programs can also identify children whose mothers seroconverted late in pregnancy or who became infected during breastfeeding.^{17,21} In South Africa, 9.2% of children tested in immunization clinics were found to be HIV-infected,²² suggesting this strategy would likely in identifying previously undiagnosed children. Ideally, the mother would be tested first (as the child may not be HIV-exposed), but it is appropriate to test the infant first in situations where maternal HIV status cannot be determined. However, legal regulations and cultural norms about testing the child without the presence of the mother will need to be taken into account (and may influence willingness of health care workers to participate in testing of children).

In concentrated epidemics, immunization and under-5 clinics can be used to test HIV-exposed infants who do not return for PMTCT services following labour and delivery. This will require implementation of systems to track mother-infant pairs.

A combination of these strategies, adapted for individual country settings, will be necessary to identify the children living with HIV who are currently undiagnosed: a necessary step to providing acceptable coverage of treatment services in this vulnerable population.



APPENDIX: OPERATIONAL CONSIDERATIONS

WHAT ELSE DO PROGRAMS NEED TO CONSIDER WHEN STRENGTHENING HTC SERVICES FOR INFANTS, CHILDREN AND ADOLESCENTS?

Beyond basic testing strategies, other considerations are critical for successful implementation of effective pediatric testing scale-up. These should be taken into account in any setting where case identification of HIV-infected children is receiving PEPFAR support.

1. LINK ALL INFANTS, CHILDREN, AND ADOLESCENTS IDENTIFIED AS HIV-INFECTED TO HIV CARE AND TREATMENT SERVICES AND ESTABLISH ALL ART-ELIGIBLE CHILDREN ON ART AS SOON AS POSSIBLE

An HIV diagnosis without linkage to HIV care and treatment services confers little or no benefit to the child. Strengthening linkage to care for all children diagnosed as HIV-infected will require close coordination between HTC and HIV clinical care programs. Any programs providing HIV testing for children (e.g. HTC, ANC, PMTCT, EID, TB, OPD) must assume responsibility for linking children they have identified as HIV-infected to HIV care and treatment services. Once this linkage has taken place, HIV care and treatment programs can then assume responsibility for retaining children in care for clinical monitoring, ART initiation, and viral suppression.

Several promising practices have been identified to improve linkage to care among pediatric patients. These include:

- a) **Assigning HIV-infected mothers and their HIV-exposed infants a unique ‘mother-infant’ pair identifying number.** This number can help programs track the mother and infant together instead of as two separate patients, allowing programs to identify infants whose mothers are HIV-infected but for whom no HIV test results are available. Providers and/or community health workers can then follow-up with infants whose HIV test results are missing or HIV-infected infants who remain unenrolled in care.²⁰
- b) **Documenting the child’s ART number in the HTC or EID register** allows programs to confirm linkage to care and identify infants in need of further follow-up.
- c) **Working with community health workers to track mother-infant pairs strengthens the link between community and facility programs.** In Malawi, community health workers track mother-infant pairs from the mother’s diagnosis during antenatal care until either a definite negative diagnosis for HIV-exposed infants or confirmed entry into clinical care for HIV-infected infants. Under this program, 77% of infants have been tested for HIV, and of those found to be HIV-infected, 92% have been successfully linked to HIV clinical care.¹⁴
- d) **Offering integrated HIV care and treatment services to entire families or mother-baby pairs** can help remove the opportunity costs associated with seeking HIV clinical care and has been shown to improve the number of infants and children enrolled in HIV care and treatment services following an HIV diagnosis.²³
- e) **For older children not eligible for treatment upon diagnosis, point of care technologies including CD4 count and viral load testing** allow clinical staging at the time of the HIV diagnosis and have been shown to improve linkage to care.²⁰

Adopting a “linkage to care” indicator can also help HTC programs monitor the number of HIV-infected children linked to HIV care and treatment services following an HIV diagnosis. A suggested indicator for measuring linkage to care is “the number of HIV-infected adults and children who are enrolled in care services and received at least one of the following at enrollment: clinical assessment (WHO staging) OR CD4 count OR viral load within 3 months of their HIV diagnosis” divided by “the number of individuals with an HIV diagnosis in the past 12 months.” Disaggregating this indicator by age would allow programs to distinctly monitor linkage to care for infants, children, adolescents, and adults.

2. SET APPROPRIATE TARGETS FOR PEDIATRIC CASE FINDING AND TREATMENT

Setting ambitious yet attainable targets for pediatric case finding and treatment can help mobilize and advocate for financial and human resources, and can hold programs accountable by giving them specific numbers against which to measure progress.^{25–26} HTC programs, in conjunction with pediatric care and treatment colleagues, should set targets aimed at increasing the coverage of HIV testing services for infants and children (e.g. testing 85% of all children in TB clinics and/or 100% of children of adults attending an HIV care service). Pediatric testing targets should be aligned with pediatric treatment targets to ensure enough children are tested and enough HIV-infected children are identified to reach the pediatric treatment targets. In order to achieve this, coordination and communication between HTC and HIV clinical programs is critical. Whenever possible, pediatric testing and treatment targets should be set at multiple levels including national, district, and facility.

To measure progress towards meeting coverage targets, record keeping needs to be improved in order to assess whether providers are offering testing to patients, the age of patients being tested or refusing testing, and their results. HTC programs will also need to develop tools that track the number of infants, children, and adolescents admitted at different service entry points (e.g. TB clinics, malnutrition services, in-patient wards) and the number of infants, children, and adolescents tested within those service entry points, to calculate the coverage of HTC services.

3. OPTIMIZE DOCUMENTATION OF SERVICES TO MONITOR AND EVALUATE EFFECTIVENESS OF CASE-FINDING STRATEGIES IN CHILDREN

All HIV testing and counseling (HTC) programs should continually monitor their routine program data to ensure they are targeting their services appropriately. Careful documentation at the point of service delivery is the necessary first step to effective monitoring, so that strategies can be continuously refined based on country-based results. Additionally, programs should routinely collect cost and expenditure data. Linkages should be monitored as well (e.g. OVC referrals, HTC-identified cases enrolling in care). It is acceptable, and sometimes encouraged, for national programs to document and monitor indicators which are not required by governments or funding organizations (such as PEPFAR) if programmatic improvement can result.

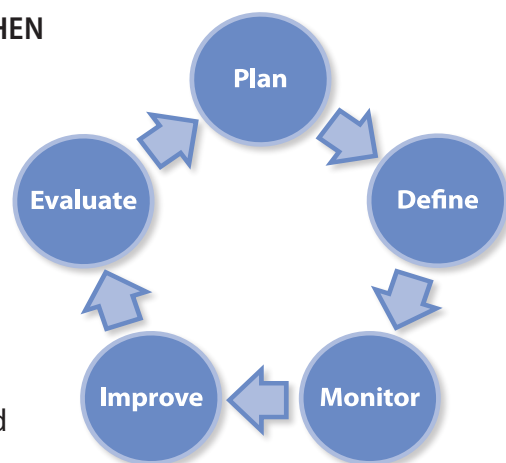
At a minimum, programs should use their data to determine:

- progress towards meeting targets of children tested;
- yield (defined as the percent of tested children who are identified as HIV-infected, by site);
- cost per case identified; and
- cost per child reached with HTC services.

4. USE A QUALITY IMPROVEMENT APPROACH TO STRENGTHEN PEDIATRIC CASE FINDING AND LINKAGE TO CARE

HTC programs should consider adopting a quality improvement approach to improve and strengthen pediatric case finding and linkage to care. Under this approach, programs first establish indicators and targets related to pediatric case finding and linkage to care. Examples of potential indicators include:

- “of all children admitted to hospital, the number and proportion who received an HIV test”,
- “of the total number of children tested, the number and proportion of HIV-infected children identified,”
- “of all women in PMTCT, the number and proportion of HIV-exposed infants receiving a PCR test by 8 weeks of age,” or
- “of all children under 5 years of age diagnosed with HIV, the number and proportion who are initiated on ART within one month of diagnosis.”



Several countries (e.g. Uganda and Kenya) have developed electronic EID dashboards that report EID results in real time. These databases can also be used to track the number of HIV-infected infants linked to ART services. Once programs have established appropriate indicators and targets, routine program data can be used to monitor progress towards achieving these targets. Programs not meeting their identified targets can then develop interventions to address programmatic challenges and gaps and improve program performance. In addition, program managers at the regional and district level can provide supportive supervision and mentoring to health facilities and HTC programs struggling to meet their performance targets.

5. USE TASK SHARING TO EASE HUMAN RESOURCE CONSTRAINTS

Training personnel at HTC sites on how to conduct pediatric testing will be needed to scale-up pediatric case finding efforts. In addition, task sharing can be used to ease human resource constraints and improve service utilization and retention. Several programs have demonstrated the efficacy of using community health workers, lay counselors, and volunteer patient escorts to provide pediatric HIV testing and counseling in inpatient wards and in community settings.^{14–19} These peer providers can also provide additional support to families, helping to retain children and their caregivers in HIV clinical services. Community health workers can also be trained to provide home-based pediatric care and support services to assist facility-based services. Task sharing to allow nurse initiation and management of pediatric ART has also enabled pediatric treatment services to be scaled-up in areas with severe physician shortages.²⁷ In addition, many families seek care for infants and children from traditional healers, especially around the neonatal period (e.g. when the umbilical cord is falling off) and around the time of weaning. Training traditional healers to remind mothers of HIV-exposed infants to take their children to a health facility for an HIV test may be one strategy to increase the number of infants who receive an HIV test at the recommended ages. However, further evaluation will be needed to test the effectiveness of this strategy. In addition, to be successful, task sharing strategies will require supportive policies and regulatory guidelines, definition of clear roles and expectations for all involved staff, and provision of appropriate supportive supervision.^{28–29}

6. SECURE THE COMMODITY SUPPLY CHAIN

Pediatric HTC services cannot be provided without an adequate supply of essential commodities, including rapid test kits, materials for early infant diagnosis, and other testing supplies (e.g. gloves, capillary tubes, lancets, etc.). For example, obtaining a dried blood spot (DBS) sample from an HIV-exposed infant requires multiple items, and the stock-out of any single item may prohibit sample collection entirely. Unfortunately, many health facilities and HTC programs report frequent stockouts of HTC commodities, placing further constraints on the ability of pediatric and adolescent patients to access HTC services. Regular monitoring and management of the entire supply chain system—including stock levels, forecasting, procurement, storage and delivery—is critical to address gaps in the supply chain and to ensure the right commodities are in the right place at the right time.³⁰ In addition, the introduction of ‘bundled’ EID commodities has improved commodity management by ensuring that all items needed for a single test are bundled together into one package for use by healthcare workers.³⁰ Further use of bundled commodities should be considered, as appropriate.

7. ADDRESS ISSUES OF AGE OF CONSENT AND DISCLOSURE WHEN EXPANDING PEDIATRIC HTC SERVICES

Age of consent for HTC varies from country to country.^{11–31} Most countries set the age of consent at 16, although South Africa, Lesotho, and Zimbabwe now allow children as young as 12 to test without parental consent.¹¹ In contrast, Burundi has set the age of consent for medical procedures (including HIV testing) at 21 years of age. For children and adolescents under the age of consent, a legal guardian is usually required to provide formal consent before the child can be tested.³² However, guidelines, developed by the WHO recommend that children be involved in the testing decision as much as possible.³² In addition, most countries recognize certain groups of adolescents—namely those who are pregnant, married, symptomatic for HIV, or who are engaged in a behavior that puts them at risk for HIV (e.g. sex work or injection drug use)—as “emancipated minors.” These emancipated minors can often consent to an HIV test without permission from a parent or guardian even if they are below the legal age of consent.³² The decision to test children who do not have parents or legal guardians, such as orphans, abandoned infants, and street children, should be made by the healthcare worker and take into account the best interests of the child.³³ HTC programs should be aware of laws and policies governing the age of consent in their area or country and develop appropriate procedures based on this legal framework to ensure that children and adolescents have access to HTC services.

Children and adolescents should be informed of their HIV status as early as possible and in an age-appropriate manner. For adolescents over the age of consent and emancipated minors, direct disclosure of HIV test results should be provided during an individual post-test counseling session with the adolescent.³⁴ HIV test results should be given to the parent, guardian, or caretaker of children and adolescents who are not emancipated minors but over the age of 10 years, ideally in the presence of the child. Children should then be offered individual post-test counseling. Children younger than 10 years of age should be told about their HIV status according to their ability to understand the information.³⁴ Further guidance on HIV disclosure counseling for children younger than 10 years can be found at: http://www.who.int/hiv/pub/hiv_disclosure/en/.

8. ADDRESS THE UNIQUE NEEDS OF ADOLESCENTS

The number of adolescents living with HIV (ALHIV) is growing for two main reasons. The first is the “aging up” of children perinatally infected in the 1990’s and early 2000’s. The second is a population boom which has led to the largest generation of adolescents and young people in history. While 40% of new HIV infections occur in young people aged 15 to 24 years, evidence indicates that adolescents are not accessing HTC and HIV clinical care services in numbers commensurate with their population.^{2, 35}

The HIV testing strategies described in figure 1 above should be used to increase the coverage of HTC services among adolescents. In addition, sexual and reproductive health clinics and medical male circumcision services should be used as service delivery points for testing adolescents for HIV. Offering HIV testing to adolescents in outpatient settings should also be considered in settings with high rates of HIV incidence and prevalence among adolescents.

The 2013 WHO Consolidated Guidelines contain new recommendations on HIV testing and counseling for adolescents.⁶ These include:

1. **HTC, with linkages to prevention, treatment, and care, is recommended for adolescents from key populations in all settings (generalized, low and concentrated epidemics).**
2. In generalized epidemics, HTC with linkage to prevention, treatment, and care is recommended for all adolescents.
3. In low and concentrated epidemics, HTC with linkage to prevention, treatment, and care is recommended to be made accessible to all adolescents.
4. **Adolescents should be counselled about the potential benefits and risks of disclosure and empowered and supported to determine if, when, how, and to whom to disclose.**



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ALHIV face a unique set of challenges that may not be adequately addressed through pediatric or adult-focused programs. Thus, adolescent-friendly services (including the elements described in Table 2) are needed to address the physical and psychological needs of this group.³⁵⁻³⁶ These needs include adherence counseling and support, sexual and reproductive health services, mental health support, and social services if homeless. Programs should also help transition adolescents from pediatric to adult ART services. Tools for managing this transition have been developed and are available at: <http://www.hivguidelines.org/wp-content/uploads/2012/11/transitioning-hiv-infected-adolescents-into-adult-care-11-06-2012.pdf>. Involving adolescents in the design, delivery, and evaluation of HIV care, treatment, and support services is also necessary to ensure these programs address their unique needs.

Table 2. Elements of Adolescent-Friendly Services

Essential	Supportive
<ul style="list-style-type: none"> • Convenient and consistent operating hours • Privacy and confidentiality • Competent (both technical and culturally) staff • Respect for adolescents • Package of essential services available • Sufficient supplies of commodities and drugs • Integrated health services where appropriate • Referrals available • Waiting time appropriate • Affordable or absent fees • Separate space and/or hours for youth 	<ul style="list-style-type: none"> • Youth input/feedback to programs • Accessible location • Publicity that informs and reassures young people • Welcoming setting • Peer educators, providers, and support • Educational materials available for girls and boys at a developmentally appropriate age • Partners, caregivers, and parents welcomed • Non-medical staff trained and supervised • Community-based outreach services available from trained workers

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