TRANSITIONING HIV-INFECTED ADOLESCENTS INTO ADULT CARE

I. INTRODUCTION

As HIV-infected adolescents grow into adulthood, it becomes necessary for them to transfer to adult care settings and take responsibility for their own health and disease management. Transition in this setting can be defined as *"a multifaceted, active process that attends to the medical, psychosocial, and academic or vocational needs of adolescents as they move from the child- to the adult-focused healthcare system. Health care transition should also facilitate transition in other areas of life as well (e.g., work, community, and school)."* [1]

Adolescents and young adults are an increasing proportion of the HIV-infected population. In 2008, 17.6% of new HIV cases in New York State were in the 13- to 24-year-old age group. In addition, more perinatally infected patients have entered this age group. The HIV-infected adolescent population comprises a mixed group of 1) perinatally infected adolescents who are now surviving into adulthood, and 2) behaviorally infected adolescents, most of whom were infected sexually. Despite sharing some common characteristics, these two populations are quite distinct with respect to their needs and challenges.

The American Academy of Pediatrics defines adolescence as 13 to 21 years of age. The recommendations in this chapter pertain to both adolescents and young adults because many pediatric and adolescent clinicians follow HIV-infected patients from 13 to 24 years of age. For guidelines that focus on the comprehensive care of HIV-infected adolescents, refer to *Ambulatory Care of HIV-Infected Adolescents*.

These guidelines have been developed to assist providers with the transition process to ensure that HIV-infected young adults are successfully and seamlessly integrated into an adult care setting. Recommendations are meant to serve as a guide and will need to be tailored to the individual patient.

Table 1 lists the cornerstones of effective transitioning that are addressed in this chapter.

TABLE 1
GENERAL PRINCIPLES FOR EFFECTIVE TRANSITIONING

- Individualize the approach used
- Identify adult care providers who are willing to care for adolescents and young adults
- Begin the transition process early and ensure communication between the pediatric/adolescent and adult care providers prior to and during transition
- Develop and follow an individualized transition plan for the patient in the pediatric/adolescent clinic; develop and follow an orientation plan in the adult clinic. Plans should be flexible to meet the adolescent's needs
- Use a multidisciplinary transition team, which may include peers who are in the process of transitioning or who have transitioned successfully
- Address comprehensive care needs as part of transition, including medical, psychosocial, and financial aspects of transitioning
- Allow adolescents to express their opinions
- Educate HIV care teams and staff about transitioning

II. Challenges and Barriers to a Successful Transition

Common barriers have been identified in the literature regarding transition of adolescents with chronic diseases into adult care.[2-14] Many young patients experience worry and anxiety about transitioning and have a difficult time adjusting to the increased responsibility and expectations in an adult care setting.[15-17] Issues specific to HIV-infected youth may make the transition more difficult for this population compared with adolescents with other chronic illnesses (see Appendix A, *Challenges to Successful Transitioning*).[18]

Transition to an adult care setting is a challenge for most HIV-infected adolescent patients because of the loss of the stable and long-term nature of their relationships with their pediatric or adolescent healthcare team.[19] HIV-infected adolescents who have lost family members or are estranged from their families may feel that their pediatric or adolescent care providers have become their primary support system. Transitioning to an adult care setting abruptly or without preparation may result in the patient withdrawing from medical care altogether because the adolescent is left feeling "dumped" or abandoned, which may further exacerbate a perception of overall loss.

Appendix A, *Challenges to Successful Transitioning*, lists common challenges of transition, HIV-specific challenges, and challenges specific to both perinatally and behaviorally infected adolescents.

III. Preparing for Transition in the Pediatric/Adolescent Care Setting

Recommendations:

The pediatric/adolescent care provider should:

- **Develop a transition plan several years prior to transition and update it at regular intervals** (AIII)
- **Ensure that HIV-infected youth understand their chronic illness and its management, and provide them with skills to negotiate care in an adult clinic setting** (see Table 3) (AIII)
- **Assess patients, in an individualized manner, for development of sufficient skills and understanding for successful transition** (AIII)
- **Address the individual barriers for each patient that may be preventing him/her from acquiring skills, such as developmental delays, anxiety, post-traumatic stress disorder, transient living conditions** (AIII)
- **Prepare and discuss a current medical history with the patient so that he/she is aware of previous hospitalizations or allergies that may have occurred during infancy or childhood** (AIII)

A. Developing a Transition Plan

RECOMMENDATIONS:
The pediatric or adolescent care provider should collaborate with the patient and family to develop a transition plan that spans several years with concrete goals and a timeline. Whenever possible, a written transition plan should be developed at least 3 years before the transition is planned and should be updated at least annually. (AIII)

For adolescents who do not yet know their HIV status, disclosure should be a primary goal of the transition plan. (AIII)

As part of the transition plan, arrangements should be made for transitioning patients to meet their new providers well in advance of their final appointment with their pediatric or adolescent primary care provider. (AIII)

It is recommended that providers plan to take at least 3 years to prepare patients for the transition to an adult practice setting. The transition plan, together with individual goals and achievements, should be reviewed and modified annually. See Appendix B, S*ample Policies, Tools & Assessments*, for examples of transition instruments.

There are unique clinical considerations that should be considered when developing transition plans for perinatally infected adolescents (see Table 2). Disclosure of HIV status is a prerequisite for transition to adult care. For guidelines on disclosure, see *Disclosure of HIV to Perinatally Infected Children and Adolescents*.

TABLE 2
CLINICAL CONSIDERATIONS IN PERINATALLY INFECTED VS BEHAVIORALLY INFECTED ADOLESCENTS

Perinatally Infected	Behaviorally Infected
• More likely to be in advanced stages of HIV disease and immunosuppression • More likely to have history of OIs with complications • ART is more likely to be necessary to control viremia and increase CD4 counts • More complicated ART regimens • More likely to have multidrug resistant virus and heavy antiretroviral exposure history • More complicated non-antiretroviral medications, such as OI prophylaxis and treatment • Greater obstacles to achieving functional autonomy due to physical and developmental disabilities/greater dependency on family • When pregnant, higher risk of complications due to more advanced disease and higher risk of second-generation HIV transmission due to multiple-drug resistance • Suboptimal immune response to immunizations and boosters	• More likely to be in earlier stages of HIV disease • Fewer OI complications • More likely to have higher CD4 counts* • When ART is initiated, simpler regimens can be used • Less likely to be resistant to antiretroviral drugs • Fewer developmental delays than in perinatal group, which may improve treatment adherence • More likely to achieve functional autonomy

* See *Antiretroviral Therapy: Deciding When to Initiate ART*.
ART, antiretroviral therapy; OI, opportunistic infections.

B. Education and Skills Training for Adolescent Patients

RECOMMENDATIONS:
The pediatric or adolescent care provider should offer training and practice in the specific skills that the patient will need in the adult clinic setting and should evaluate the patient's progress toward these goals (see Table 3)**.** (AIII)

The pediatric or adolescent care provider should ensure that HIV-infected youth understand their chronic illness and its management. (AIII)

Patients cannot self-manage a chronic illness when they do not understand what the illness is. They should understand the basic biology of HIV, why their medications and treatments are necessary, and how to prevent transmission. Informed decision-making is the key to mature self-care and is the overall goal for successful transitioning.

Table 3 lists the necessary skills for adolescents to engage successfully in adult care. Acquisition of these skills will help patients develop the ability to manage appointments, identify new symptoms, obtain medication refills, and properly use medical insurance.

Pediatric/adolescent healthcare systems are usually more flexible with adolescent patients regarding clinic policies. For example, pediatric/adolescent clinics will often accommodate patients who arrive late for appointments or who do not have appointments scheduled. However, the pediatric/adolescent care team should plan to implement a more structured appointment system *prior* to transition to promote skills building and to minimize "culture shock" or feelings of abandonment in the adult program, where policies are generally followed more strictly. Some adolescent programs use peer support groups for skills training and also have skills practice sessions with medical students and residents.

TABLE 3
SKILLS TO ASSIST ADOLESCENTS IN ACHIEVING SUCCESSFUL TRANSITION TO AN ADULT CLINIC

Ideally, the adolescent should be able to do the following before transitioning:

- Know when to seek medical care for symptoms or emergencies
- Identify symptoms and describe them
- Make, cancel, and reschedule appointments
- Arrive to appointments on time
- Call ahead of time for urgent visits
- Request prescription refills correctly and allow enough time for refills to be processed before medications run out
- Negotiate multiple providers and subspecialty visits
- Understand the importance of health insurance, how to select an appropriate healthcare plan, and how to obtain it and renew it
- Understand entitlements and know how to access them
- Establish a good working relationship with a case manager at the pediatric/adolescent site, which will enable the adolescent to work effectively with the case manager at the adult site

IV. IDENTIFYING THE ADULT CARE PROVIDER

RECOMMENDATION:
The referring provider should identify an adult care provider or multidisciplinary team that:

- **Is experienced with caring for transitioning HIV-infected adolescents and young adults** (AIII)
- **Is willing to engage in direct communication with the referring provider about the patient** (AIII)
- **Accepts the patient's health insurance** (AIII)

Internists and infectious disease specialists who provide adult care generally are not experienced with pediatric and adolescent developmental issues or may be averse to dealing with the behavioral issues and multiple losses that many HIV-infected adolescents face. Locating a family or hospital-based medical practice that has experience with younger patients or is willing to develop appropriate skills and knowledge may help maintain transitioning patients in care. Adult care providers who are accepting care of HIV-infected youth for the first time should work with adolescent or pediatric providers who are experienced with transitioning when developing the transition plan.

When possible, the pediatric/adolescent healthcare team should assist the adolescent in choosing an adult clinic that best suits the individual. For example, patients with comorbidities, such as hepatitis C virus co-infection, diabetes, or mental health disorders, need to be in a setting that can provide comprehensive care. Some adolescents may feel that location is the most important factor due to time and transportation restrictions. Lesbian, gay, bisexual, and transgender (LGBT) youth may be looking for an environment that is "gay-friendly."

In some pediatric/adolescent settings, it may be possible to include a family practitioner or an adult provider who divides his/her time between the adolescent and adult clinic. The adult provider then becomes a familiar member of the multidisciplinary team prior to transition.

The Importance of Using a Multidisciplinary Approach

RECOMMENDATIONS:
HIV care should be provided in settings where patients can receive all services in one location from a multidisciplinary team. If a multidisciplinary team is not available, mental health and psychosocial support services should be available onsite or in an easily accessible location. The primary care team should be responsible for maintaining an ongoing plan for coordination of care among all service providers. (AIII)

In areas where comprehensive HIV services are not available, the patient should be referred to a primary care provider with experience in providing HIV care in addition to a provider experienced with ART management. The primary care provider should help the transitioning patient navigate the adult subspecialty clinic model. (AIII)

If gynecologic services are not available as part of a comprehensive care model in the adult HIV care program, the primary care provider should refer HIV-infected adolescents/young women to a gynecologist with expertise in counseling adolescents regarding reproductive health and perinatal transmission. (AIII)

The primary care provider and members of the multidisciplinary team also should be able to provide ongoing HIV transmission and risk-reduction counseling to adolescents. (AI)

Many HIV-infected adolescents and young adults need access to complex mental health, alcohol and substance use, and psychosocial services. Unusually high rates of mental health diagnoses have been observed in both perinatally and behaviorally infected adolescent clinic cohorts.[20-25]

The primary care provider and members of the multidisciplinary team also should be able to provide ongoing HIV transmission and risk-reduction counseling to adolescents.[26] Ideally, an adult care provider who does not work with a multidisciplinary team should have access to necessary supportive services onsite or nearby. If patients need to be referred to other facilities for services, the primary care team should be responsible for maintaining an ongoing plan for coordination of care among all service providers. All providers involved in the patient's care are then aware of care plans from other providers, and staff can then follow up with patients when appointments are missed.

Key Point:
When care is complex or fragmented, assignment of a specific staff person, such as a nurse, case manager, or social worker, to a coordinating role is important to ensure that a comprehensive and effective management plan is implemented that includes optimal support and follow-up.

Onsite gynecological services, provided by either the primary care provider, a nurse practitioner, gynecologist, or nurse midwife with HIV expertise, is the best model to ensure adherence to gynecologic care. If the patient is referred to a general gynecologic service, the primary care provider needs to ensure that topics specific to HIV care, such as drug interactions between antiretroviral agents and hormonal contraceptives and "dual protection" education (consistent use of a reliable contraceptive method in addition to condoms used to prevent HIV transmission) are addressed (see *Care for the HIV-Infected Female Adolescent* and *Contraception for HIV-Infected Women*).

V. PREPARING FOR TRANSITIONING PATIENTS IN THE ADULT CARE SETTING

RECOMMENDATIONS:
The adult care provider should:

- **Become knowledgeable regarding the challenges of transition for older adolescents and young adults to an adult care setting** (AIII)
- **Prior to transition, learn from the referring provider the particular challenges and goals for the patient; consider how to continue building the adolescent's skills** (AIII)
- **Meet the patient, with or without family members, before the change in care** (AIII)
- **Assign one clinic staff member as point person and have his/her contact information available, including hours when contact is possible** (see Section VI. C. *Use of Transition Agent or Patient Advocate*) (AIII)
- **Have an orientation plan in place to acquaint the newly transitioned patient to the new clinic environment** (AIII)

The adult provider or multidisciplinary team should have a plan in place to orient newly transitioning adolescents or young adults to the adult clinical care program. The clinic and/or the provider's expectations of the newly transitioned patient should be explained during or before the first visit. The policy for late arrivals and walk-ins should be clearly explained to the adolescent.

VI. IMPLEMENTING THE TRANSITION PLAN

RECOMMENDATION:
The referring clinician or provider team should arrange the transitioning of all current and anticipated services, including medical, mental health, and substance use treatment if needed. Individualized psychosocial needs, such as housing, employment, education, insurance, home-based services, or transportation, should also be addressed at this time. (AIII)

A. When to Transition

RECOMMENDATION:
The transition plan should be implemented when the patient:

- **Demonstrates understanding of his/her disease and its management** (AIII)
- **Demonstrates the ability to make and keep appointments** (AIII)
- **Knows when to seek medical care for symptoms or emergencies** (AIII)

Whenever possible, transition should be implemented when the patient's disease is clinically stable. (BIII)

Most HIV-infected adolescents transition to adult care between 22 and 24 years of age.[27] However, developmental stage and readiness for transition may be better indicators than chronological age for determining when transition should occur. Patients with developmental delays or a chaotic and unstable life may need more time to become ready to transition. Adolescents who demonstrate independence in making their own decisions and show responsibility for their own care may be ready sooner.

The likelihood for successful transition is increased when both the pediatric/adolescent healthcare team and adult healthcare team recognize the broad spectrum of readiness in transitioning patients, ranging from those who are near full autonomy to those for whom disorder and confusion are a daily experience. For example, the transition process for a college student with well-developed career goals will be vastly different than that for a patient who is often hospitalized, nonadherent with medications, and frequently in crisis both emotionally and behaviorally. The goals and challenges of transition, as well as the support that will be needed during the process, will be individualized for each patient.

B. Communication Between the Adolescent Care Provider and the Adult Care Provider

RECOMMENDATIONS:
The referring clinician should:

- **Compose a medical summary that highlights key issues for the individual patient and includes the patient's medical, psychological, and social history** (AIII)
- **Schedule a case conference prior to transition** (AIII)

Although the adult medical model does not generally provide time for direct communication between referring and receiving providers or provider teams, coordination between these providers can moderate the "culture shock" for a patient moving from child-, adolescent-, or family-centered care to adult-centered care. Adolescent medicine experts underscore that, for effective transitioning, a written summary is necessary but not sufficient. Direct communication between providers is essential. When the pediatric or adolescent care team is informed about the orientation plan in the adult clinic, it allows them to provide the transitioning patient with realistic expectations and helps them to prepare the patient with the necessary skills for managing his/her care in the new setting.

C. Use of Transition Agent or Patient Advocate

RECOMMENDATIONS:
The adolescent care provider should designate one member of the healthcare team to oversee transition planning and implementation at both the old and new provider locations. (AIII)

The adult care provider should also designate a point person who will oversee the transition and who the patient can contact with any questions or concerns. (AIII)

The adolescent care provider or team should designate one care provider to oversee transition planning and implementation. This may be the primary care provider or another team member, such as a social worker. The coordinator should have equal visibility in and access to the pediatric and adult clinics to demonstrate continuity to the patient.

In some programs, a peer advocate, who may be someone who has recently transitioned successfully, works with the patient to create and track progress on an individualized transition plan. Peer advocates may accompany patients to the initial adult medical appointments and then provide support while they gain the independence and confidence to attend subsequent appointments by themselves.[28,29]

The adult care provider should designate a point person who the patient can call with any questions or concerns. The point person can guide the patient to appropriate services and also alert providers if there are any concerns. This may be someone different than the designated contact person for clinic patients. For example, it might be a social worker or counselor who is familiar with developmental issues for transitioning adolescents and young adults. A primary care provider may choose to be called directly, or there may be a particular nurse or other staff member who is especially adept at working with young patients.

D. Challenges for Pregnant Adolescents During Transition

RECOMMENDATIONS:

Adolescent care providers should have referral agreements with obstetrical services that can provide prenatal care to HIV-infected females during transition and that offer prenatal support services. (AIII)

Pediatric and/or adolescent care providers should be able to provide individualized support and advocacy for pregnant teens who are unprepared for transition to obstetrical services. (AIII)

Adolescent care providers should consider remaining the primary care provider for the adolescent during pregnancy. (AIII)

Adolescent pregnancy is often unplanned and can interrupt the process of transition planning and skills training. As a result, the patient may be referred to an obstetrics clinic before she is ready and well-prepared for adult care. This is a time when active support is particularly important to ensure that a patient's discomfort with receiving treatment from a new provider and clinic do not lead to interruption of either prenatal or HIV care. For recommendations regarding care for HIV infected pregnant adolescents, see *Care for the HIV-Infected Female Adolescent*.

VII. ROLE OF THE ADULT CARE PROVIDER DURING THE TRANSITION PERIOD

RECOMMENDATIONS:

The adult care provider or multidisciplinary team should:

- **Assign an appropriate clinic staff person to be the primary contact person for newly transitioned adolescents and young adult patients** (AIII)
- **Have a plan for identifying and managing problems that could interfere with continuity of care** (BIII)

Adult care providers and clinic staff need to be prepared for individual differences in maturity and ability to cope. Some of their young patients will initially require far more support and psychosocial intervention than is customary in adult care settings if they are to transition successfully. Others will have already learned the skills needed to negotiate the healthcare system, appointments, and prescriptions and are eager to become self-sufficient adults. These patients likely only need to be educated about what is expected of them as patients in the new adult care setting.

The adult medical model does not generally allow for the extra time that may be needed for patients who are still learning how to speak for themselves and make mature decisions. The adult care provider and healthcare team should strive to devise ways to provide adequate time for the patient during the transition adjustment period.

Clinicians should strive to have a nonjudgmental approach to patient communication, especially when discussing sexual behaviors. Adolescents/young adults often tend to disengage from care if they feel that they have been spoken to in a judgmental manner.

Adult programs generally have more policies than pediatric and adolescent clinics. Policies for late arrivals and walk-ins should be clearly explained to the adolescent; however, to the extent possible, adult programs should also attempt to be flexible to accommodate the frequently less predictable schedules of adolescents/young adults.

VIII. Evaluation After Transition Has Occurred

A. Post-Transition Assessment by the Adult Care Provider or Team

Recommendation:
The adult care provider or team should devise a plan to achieve the following on an ongoing basis:

- **Assessment of whether an individual patient is adequately caring for his/her own health** (AIII)
- **Assessment of barriers that the patient is facing, what support is needed, and who will provide this support** (AIII)
- **Skills training and support, either through the multidisciplinary team in the clinic or by liaison with a mental health or psychosocial support provider** (AIII)

Many adolescents and young adults transitioning to adult clinics will not have much experience in practicing the healthcare behaviors that often develop with maturity. The adult care provider should be alert to signs that a young patient needs additional support or skills training. Offering immediate support will reduce the risk of the patient withdrawing from care. Any one of the following behaviors may alert the clinician that the patient requires additional support and indicates a need to revise the individual's transition plan:

- Multiple missed appointments
- Discontinuation of medications
- Substance use or other behaviors suggestive of poor adjustment
- Loss of entitlements
- Unstable housing

The checklist in Table 4 can be used to evaluate the success of the transition.

TABLE 4 CHECKLIST FOR SUCCESSFUL TRANSITION
☐ The patient has accepted his or her chronic illness and is oriented toward future goals and hopes, including long-term survival.
☐ The patient has learned the skills needed to negotiate appointments and multiple providers in an adult practice setting.
☐ The patient has achieved personal and medical independence and is able to assume responsibility for his or her treatment and participate in decision-making.
☐ The referring provider is familiar with the new provider and practice setting, and direct communication about an individualized plan for the patient has taken place.
☐ Mental health services have been transitioned at the same time as medical services.
☐ Psychosocial needs are met and entitlements are in place (housing, health insurance, home care, transportation).
☐ Life skills have been addressed (e.g., educational goals, job training, parenting).
☐ The patient receives uninterrupted comprehensive medical care.

B. Follow-up From Adolescent or Pediatric Care Provider

RECOMMENDATION:
If adolescents withdraw from care in the adult clinic and return to their previous pediatric/adolescent clinic, the adolescent care provider should be prepared to help the patient identify services that can provide increased support and should encourage re-engagement in adult medical care. (AIII)

After transitioning to an adult care setting, patients may continue to have contact with their pediatric/adolescent care team providers, which may reinforce a successful transition or may uncover potential pitfalls in maintaining ongoing care at the adult facility. Therefore, continued communication between adult and pediatric providers remains a crucial aspect of the transition process.

Both the patient's and the pediatric/adolescent care provider's desire to "check in" at the beginning of the transition process is part of normal and healthy closure and can mitigate the patient's sense of loss. However, transitioning patients may continue to rely on their pediatric/adolescent care provider for emotional support. This provider should defer clinical management decisions to the new provider and should be alert to the risk of hindering the patient from establishing a trusting therapeutic relationship with his/her adult care provider.

Young patients who withdraw from care in an adult clinic will often return to their adolescent or pediatric provider. When this happens, the provider should be prepared to help the patient identify services that can provide increased support and should encourage re-engagement in adult medical care.

IX. ONLINE RESOURCES

- Adolescent Health Transition Project website: Information on transitioning for teens, families, and healthcare providers and educators. Available at: http://depts.washington.edu/healthtr

- Adolescents Living With HIV (ALHIV) toolkit. Available at: http://www.k4health.org/toolkits/alhiv

- AIDS Alliance for Children, Teens, and Families. *Transitions in Health Care: A Guide for Teens with HIV/AIDS and Their Families.* Available at: http://www.aids-alliance.org/resources/publications/transitionshealthcare.pdf

- AIDS Training and Education Centers National Resource Center. Practitioner Transition Checklist and Timeline. Available at: http://www.aids-ed.org/aidsetc?page=et-adol-checklist

- Birnbaum JM. Transitional Care for HIV and AIDS from Adolescence to Adulthood. Slide presentation. Available at: http://www.hivguidelines.org/Admin/Files/ce/slide-presentations/trans-care.ppt

- Casey Life Skills website: Provides tools and teaching resources for young people to prepare for adulthood. Available at: http://caseylifeskills.org

- Healthy & Ready to Work National Resource Center – Tools and checklists
    - Assessment Tools: http://www.hrtw.org/tools/check_assessment.html
    - Provider Checklist: http://www.hrtw.org/tools/check_provider.html
    - Care Plans—forms and transition summaries: http://www.hrtw.org/tools/check_care.html

- HIV Clinical Resource website provides clinical guidelines on the care of adolescents with HIV infection. Available at: http://www.hivguidelines.org/clinical-guidelines/adolescents
    - Disclosure of HIV to Perinatally Infected Children and Adolescents
    - Ambulatory Care of HIV-Infected Adolescents
    - Care for the HIV-Infected Female Adolescent
    - Substance Use and Dependence Among HIV-Infected Adolescents and Young Adults

- HRSA Care ACTION. *Transitioning from Adolescent to Adult Care*. June 2007. Available at: ftp://ftp.hrsa.gov/hab/june2007.pdf

- Kentucky Commission for Children with Special Health Care Needs. *Transition Developmental Checklist.* Available at: http://chfs.ky.gov/nr/rdonlyres/8c5eedbe-14fc-4488-8c85-1bac1ede0516/0/checklist.pdf

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APPENDIX A. CHALLENGES TO SUCCESSFUL TRANSITIONING

CHALLENGES TO SUCCESSFUL TRANSITIONING	
Common Challenges in Transitioning Adolescents with Chronic Illnesses	▪ *Identifying adult care providers* who are willing and/or versed in transitional care ▪ *Difficulty for pediatric or adolescent care team in separating from long-term patients* who may think of their healthcare team as surrogate family[1] ▪ *Adolescent and/or family resistance to change*[1] ▪ *Radical differences in expectations and clinic cultures* between pediatric/adolescent and adult care settings ▪ *Communication difficulties* between adolescents and adult care providers ▪ *Inadequate time and resources in adult medicine practice settings* for young patients who may require extensive psychosocial support ▪ *Insurance lapses* and non-reimbursable duplication of services during the change ▪ *Adolescents may not know what services are available or how to navigate the adult healthcare delivery system*
HIV-Specific Challenges (*applicable to both perinatally and behaviorally infected adolescents*)	▪ *Stigma* of being infected with HIV and, for many HIV-infected youth, the additional stigma of being gay, transgender, a substance user, or a teenage mother ▪ *Increased need for mental health, substance use, and psychosocial services* in the HIV-infected population and the complexity of transitioning such services simultaneously ▪ *High rates of teen pregnancy* ▪ *Non-disclosure to partners or roommates with whom they are living* ▪ *Experience of multiple losses for many HIV-infected youth* ▪ *Limited social support* ▪ *Fear of seeing sick patients in adult clinic and the reminder of the illness they share* or not identifying with the older patients they may see in the adult clinic ▪ *Lack of HIV providers* with expertise to treat this population in rural areas *Continued on the next page*

Challenges Specific to Perinatally Infected Adolescents	▪ *Non-disclosure by parent or guardian* – some patients may not have been told that they are HIV-infected ▪ *Loss of emotional support and sense of belonging* –many perinatally infected adolescents have been lifelong patients in one clinical setting; for patients who have lost parents and other family members or friends, transitioning may mirror earlier losses and bereavement experiences ▪ *Obstacles in achievement of milestones* that are necessary for obtaining and maintaining employment (e.g., long-standing cognitive delays, excessive absences from school, lack of role models, perception during their formative years that HIV would prevent them from living to adulthood, physical stigma, such as short stature, lipodystrophy, encephalopathy) ▪ *More complex clinical issues* than behaviorally infected adolescents (see Table 2)
Challenges Specific to Behaviorally Infected Adolescents	▪ *Non-disclosure to primary caregiver* – one study found that one-third of youth do not disclose their HIV status to their mother or mother figure[2] ▪ *High rates of homelessness and incarceration*[3]

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APPENDIX B. SAMPLE POLICIES, TOOLS & ASSESSMENTS

The following resources contain examples of transition tools for individual facilities to develop for their own use

1. Transition Tool
Tool to be used by provider to assess the adolescent's knowledge of the following:

- HIV and its management
- Preventive health and safer-sex behaviors
- Use of health insurance
- Community resources

2. Adolescent Individualized Transition Plan

- This plan should be based on the patient's needs and interests

3. Transition Healthcare Assessment

- The adolescent should fill out this sheet so the provider can assess his/her transitional needs
- Use the results to discuss needs with the adolescent

Sample forms 1 – 3 adapted, with permission, from Jacob S, Jearld S. *Transitioning Your HIV+ Youth to Healthy Adulthood: A Guide for Health Care Providers.* Children's Hope Foundation, Partnership for Family Health, and Bellevue Hospital Center, New York City Health and Hospitals Corporation. April 2007.

4. Skills Checklist — Project Stay

5. Transition Assessment — SUNY Downstate HEAT Program

6. Transition Policy — The PATH Center at the Brooklyn Hospital Center

➢ 1. Transition Tool

Name: DOB: MR#:	< 11 Years of Age		11 to 14 Years of Age		15 to 24 Years of Age	
Date Initiated: Date Disclosure:	Discussed	Achieved	Discussed	Achieved	Discussed	Achieved
Knowledge of Health Condition and Management						
Child interacts directly with health care team, asks questions.						
Assess child's knowledge and perception of diagnosis. Build on their understanding.						
Assess adolescent/family's readiness and assist with disclosure.						
Able to answer "What is HIV?"						
Able to answer "What are T cells?"						
Able to answer "What is a viral load?"						
Verbalizes names and dosages of medications.						
Verbalizes rules for taking medications (with food, etc).						
Able to fill prescriptions and obtain refills.						
Verbalizes known possible side effects of medications.						
Takes medications independently.						
Able to independently make appointments.						
Able to independently give history.						
Verbalizes when and how to call the doctor.						
Verbalizes when and how to access urgent/emergent care.						
Able to set up transportation for appointments.						
Keeps calendar of appointments.						
Able to identify members of the health care team, roles and how to contact.						

White areas are suggested ages to address individual skills but plans would be individualized based on development, social situation and time of entrance into program. Please date and initial discussion/achievement boxes.

Continued on the next page

➢ 1. Transition Tool, continued

Name: DOB: MR#:	< 11 Years of Age		11 to 14 Years of Age		15 to 24 Years of Age	
Date Initiated: Date Disclosure:	Discussed	Achieved	Discussed	Achieved	Discussed	Achieved
Adolescent Engages in Preventive Health Behaviors						
Visiting dentist every 6 months.						
Current with immunizations and health screenings.						
Engages in preventive behaviors (exercise, nutrition, TSE, BSE, etc).						
Abstains from using alcohol, drugs, cigarettes and/or of risk reduction behaviors.						
Adolescent Demonstrates Knowledge of Responsible Sexual Activity						
Identifies high risk situations for exploitation and victimization.						
Knowledge of contraception options, STDs, STD prevention.						
Understands implications of diagnosis on pregnancy.						
Adolescent Demonstrates Knowledge of Health Insurance Concerns and Issues						
Identifies when eligibility terminates for health insurance.						
Verbalizes type of insurance, limits of coverage, how to contact.						
Knowledge of AIDS Insurance Continuation Program.						
Adolescent Demonstrates Knowledge of Community Resources						
Case Management – THAP, etc						
Support Groups						
ADAP: AIDS Drug Assistance Program						

White areas are suggested ages to address individual skills but plans would be individualized based on development, social situation and time of entrance into program. Please date and initial discussion/achievement boxes.

➢ 2. Adolescent Individualized Transition Plan

Pre-21-year-old Transition Assessment

Projected Date:

Participants:

Education/vocation/career plan:

Family support:

Housing/goals for independent living:

Transportation:

Funding (insurance/copay/prescriptions/OTC/SSI):

Discuss timing of transition to adult care:

Other:

Plan:

Signature:

Continued on the next page

➢ 2. Adolescent Individualized Transition Plan, continued

24-year-old Transition Assessment

Projected Date:

Participants:

Education/vocation/career plan:

Family support:

Housing/goals for independent living:

Transportation:

Funding (insurance/copay/prescriptions/OTC/SSI):

Transition to adult care, choose provider:

Plan:

Signature:

Initial adult care appt: Physician: Phone:

Records release consent signed: Records forwarded:

First appt follow-up phone call:

3 month follow-up phone call:

University of South Florida, Pediatric Infectious Disease

➢ 3. Transition Healthcare Assessment

Do You Understand Your Health Condition and How to Take Care of Yourself? **Circle one:**				
1. Do you understand what caused your medical condition?	Yes	No	Not Sure	
2. Do you understand the changes/symptoms caused by your medical condition?	Yes	No	Not Sure	N/A
3. Do you manage your own daily treatment needs?	Yes	No	Sometimes	
4. Do you have any problems with your daily treatment needs?	Yes	No	Sometimes	
5. Do you understand the tests (blood, x-ray) you have to take?	Yes	No	Not Sure	
6. Do you know how to prevent spreading this to others?	Yes	No	Not Sure	
Do You Know What to Do to Keep Healthy? **Circle one:**				
1. Do you have a Primary Care Physician (PCP) that you see at least once a year?	Yes	No	Not Sure	
2. Are your shots up to date?	Yes	No	Not Sure	
3. Do you use alcohol, cigarettes, drugs?	Yes	No	Sometimes	
4. Do you have unprotected sex?	Yes	No	Sometimes	N/A
5. Do you exercise 3 times a week or more?	Yes	No	Not Sure	
6. Do you see a dentist every 6 months?	Yes	No	Not Sure	
7. Do you brush and floss your teeth daily?	Yes	No	Sometimes	
Do You Know What to Do to Keep Safe? **Circle one:**				
1. Do you have a phone to use in case of an emergency?	Yes	No	Sometimes	
2. Do you have the phone numbers of family and friends to call in emergencies?	Yes	No		N/A
3. Do you have the phone numbers of health and non-health emergency services, such as poison control, fire, and police?	Yes	No	Not Sure	
4. Do you know where the closest emergency room is?	Yes	No	Not Sure	
Do You Know How to Monitor Any Special Healthcare Needs? **Circle one:**				
1. Can you recognize when you are getting sick?	Yes	No	Sometimes	
2. Do you know when you need to call the doctor?	Yes	No	Sometimes	

Continued on the next page

➢ 3. Transition Healthcare Assessment, continued

Do You Know How to Manage Healthcare Needs? **Circle one:**				
1. Are you responsible for making your own appointments?	Yes	No	Sometimes	
2. Are you responsible for refilling your own medications?	Yes	No	Sometimes	
3. Do you know what pharmacy you use and have their phone number handy?	Yes	No	Not Sure	
4. Do you know the names and doses of your medications?	Yes	No	Not Sure	N/A
5. Do you know the common side effects?	Yes	No	Not Sure	N/A
Do You Know How to Communicate with Healthcare Providers? **Circle one:**				
1. Do you know where to look for answers to your health questions?	Yes	No	Sometimes	
2. Do you feel comfortable asking questions at your appointments?	Yes	No	Sometimes	
3. Do you know how to contact your social worker or case manager?	Yes	No	Not Sure	
Do You Know How to Community Services? **Circle one:**				
1. Have you used services in your community?	Yes	No	Sometimes	
2. Do you discuss your healthcare needs with your school nurse?	Yes	No	Sometimes	
Do You Demonstrate Responsible Sexual Activity? **Circle one:**				
1. Are you able to provide a reliable sexual history?	Yes	No	Not Sure	N/A
2. Do you know what an STD is and how it can affect you?	Yes	No	Not Sure	N/A
3. Do you have enough information about birth control and ways to prevent STDs?	Yes	No	Not Sure	
Do You Obtain Information and Reproductive Counseling When Needed? **Circle one:**				
1. Do you understand how your medical condition affects becoming pregnant or having a child?	Yes	No	Not Sure	N/A
2. Do you understand the problems associated with an unplanned pregnancy?	Yes	No	Not Sure	N/A
3. Do you think you understand the responsibilities of being a parent?	Yes	No	Not Sure	

Continued on the next page

➢ 3. Transition Healthcare Assessment, continued

Do You Keep Track of Your Health Records? Circle one:				
1. Do you have a copy of your health records, doctor contact number, and address?	Yes	No	Not Sure	
2. Do you have an insurance card or copy of it?	Yes	No		N/A
3. Do you have a method of keeping track of your healthcare appointments?	Yes	No		
Do You Have Knowledge of Health Concerns and Issues? Circle one:				
1. Do you know the rules and requirements of your health insurance?	Yes	No		N/A
2. Are you able to cover expenses not covered by your insurance?	Yes	No		N/A
3. Have you applied for income assistance, SSI, or other public service?	Yes	No		N/A
Do You Use Transportation Safely? Circle one:				
1. Do you have a driver's license?	Yes	No		N/A
2. Do you use buses or other forms of public transportation?	Yes	No	Sometimes	N/A
3. Do you use bus or other travel schedules for getting rides?	Yes	No	Sometimes	N/A
4. Do you have the money you need to get bus passes or use your car?	Yes	No	Sometimes	N/A
5. Do you have any problems in getting to where you need to go?	Yes	No	Sometimes	N/A
6. Do you use Medicaid Share Van, Medicaid Cab?	Yes	No	Sometimes	N/A
7. Do you feel safe taking the bus, van, or driving?	Yes	No	Sometimes	N/A
8. Do you know how much time you need to get to your appointments on time?	Yes	No	Sometimes	N/A
Comments or Questions:				
Name:		DOB:		MR#

Adapted from California Healthy and Ready to Work transition materials, 1 MCJ D6HRW9-01-0, University of Southern California, Department of Nursing: www.cahrtw.org

➢ 4. Skills Checklist — Project STAY

The following handout can be used to prompt older adolescents to think about the information they will need to know in an adult care setting. Recently transitioned young adults can use the handout as a reminder of the issues they need to address with their current provider.

Taking Charge of Your Health Care:
A Handout for Adolescents and Young Adults with Special Health Care Needs

› Be Your Own Health Care Advocate

- Learn about your condition.
- Know the warning signs that mean you need emergency help.
- Know who to call in case of an emergency, and carry that information with you.
- Learn how to make your own appointments.
- Write down any questions you have before you go to the doctor's office.
- Meet privately with your health care providers.
- Speak up and ask your health care provider questions. If you don't understand the answer, ask again.
- Talk to your doctor about difficult topics like relationships, drugs, and birth control.
- Ask for copies of medical tests and reports.
- Carry your insurance card and other important health care information.

› Take Charge of Your Health Care Information

- Be sure to understand the medications that you are taking. What are their names and when do you take them?
- Know how to call your pharmacy and how to fill your prescriptions.
- Make sure you know your insurance and how to get a referral.
- Keep a list of addresses and telephone numbers of all your health care providers and community resources.
- Keep a notebook of medications, medical history, and results of medical tests.
- Ask health care provider for a short written summary of your health condition.
- Know how to order and take care of any special supplies you use.

› Plan for Transfer to an Adult Health Care Provider

- Talk to your doctor and know how and when you should start seeing an adult doctor.
- Discuss with providers resources that might be helpful to you.
- Meet and talk with the new health care provider before you switch.

Adapted with permission from materials produced by the Institute for Community Inclusion at Children's Hospital, Boston, as part of the Massachusetts Initiative for Youth with Disabilities, a project of the Massachusetts Department of Public Health. Supported in part by project #HO1MC00006 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

➢ 5. Transition Assessment — SUNY Downstate HEAT Program

Name:……Date:……

DOB:……..Gender:……

Please Circle One:

Knowledge of your health:

1. Do you understand what caused your medical condition?..... Y**es No N/A**

2. Do you understand the changes caused by your medical condition?..... Y**es No N/A**

3. Do you manage your daily treatment needs?..... Y**es No N/A**

What are they?.....

.....

4. Do you have any problems with your daily treatments?.....Y**es No N/A**

What are they?.....

.....

5. Do you understand the action of the medications you take?.....Y**es No N/A**

6. Do you have understanding of the laboratory tests you have?.....Y**es No N/A**

Explain:……

.....

7. Do you know the results of your latest blood test?.....,,,,,,,,,,,,,,,,,,,,,Y**es No N/A**

8. What are they?

T-cell:……..**Viral load:**……

Continued on the next page

➢ 5. Transition Assessment — SUNY Downstate HEAT Program, continued

Please Circle One:

What you do to keep healthy:

1. Do you have a doctor that you see regularly?.....Y**es** **No** **N/A**

Who is it?.....

2. Are you up to date with immunizations and healthcare screening?.....Y**es** **No** **N/A**
3. Do you use alcohol?.....Y**es** **No** **N/A**
4. Do you use cigarettes?.....Y**es** **No** **N/A**
5. Do you use drugs?.....Y**es** **No** **N/A**
6. Do you engage in unprotected sex?.....Y**es** **No** **N/A**
7. Do you exercise regularly?.....Y**es** **No** **N/A**

If yes, what do you do?.....

How often?.....

8. Do you see a dentist on a regular basis?..... Y**es** **No** **N/A**
9. Do you brush and floss your teeth?..... Y**es** **No** **N/A**
10. Do you know when you're getting sick such as a cold?..... Y**es** **No** **N/A**

What to do in an emergency:

1. Do you have a phone to use in case of an emergency?.....Y**es** **No** **N/A**
2. Do you have phone numbers of friends and family to call in case of an emergency?.....Y**es** **No** **N/A**
3. Do you know where the closest ER is?.....Y**es** **No** **N/A**

Know how to manage your healthcare needs:

1. Are you responsible for making appointments with your providers?.....Y**es** **No** **N/A**
2. Are you responsible for refilling your medications?.....Y**es** **No** **N/A**
3. Do you have an attendant, home health aide?.....Y**es** **No** **N/A**
4. Are you responsible for their supervision?.....Y**es** **No** **N/A**
5. Do you hire the attendants that you need?.....Y**es** **No** **N/A**

Continued on the next page

➢ 5. Transition Assessment — SUNY Downstate HEAT Program, continued

Please Circle One:

Know how to communicate effectively:

1. Do you know how to seek answers to health related concerns?.....Y**es** **No** **N/A**
2. Are you able to ask questions of your providers?.....Y**es** **No** **N/A**
3. Are you able to make contact with teen/young adult support groups/camp?.....Y**es** **No** **N/A**

Know how to use community resources:

1. Do you know how to get services in your area?.....Y**es** **No** **N/A**
2. Have you used services in your area?.....Y**es** **No** **N/A**
3. Are you able to use community transportation when you need it?.....Y**es** **No** **N/A**

Demonstrates responsible sexual activities:

1. Are you able to avoid dangerous situations (victimization)?.....Y**es** **No** **N/A**
2. Are you able to provide a reliable sexual history?.....Y**es** **No** **N/A**
3. Do you know what an STD is and how it can affect you?.....Y**es** **No** **N/A**
4. Do you know about contraception and ways to prevent STDs?.....Y**es** **No** **N/A**

Information regarding reproductive health:

1. Do you know when to seek birth control counseling?.....Y**es** **No** **N/A**
2. Do you understand the problems associated with teenage/unplanned pregnancies?....Y**es** **No** **N/A**
3. Do you think you understand the responsibilities of being a parent? .....Y**es** **No** **N/A**

Keep track of health records:

1. Do you have a copy of your health records?.....Y**es** **No** **N/A**
2. Does your doctor/dentist have a copy of your health records?.....Y**es** **No** **N/A**
3. Do you have an insurance card or copy of it?.....Y**es** **No** **N/A**
4. Do you have a method of keeping track of your health appointments?.....Y**es** **No** **N/A**

Continued on the next page

➢ 5. Transition Assessment — SUNY Downstate HEAT Program, continued

Please Circle One:

Knowledge of health insurance and issues:

1. Do you know the eligibility requirements for your health insurance?.....Y**es** **No** **N/A**
2. Have you applied for income assistance (SSI) and other public services?.....Y**es** **No** **N/A**

What are they?.....

……

Uses transportation safely:

1. Do you have a driver's license?.....Y**es** **No** **N/A**
2. Do you use the buses, trains and/or other types of public transportation?.....Y**es** **No** **N/A**
3. Do you have the money you need to get bus passes/use your car?.....Y**es** **No** **N/A**
4. Do you have any trouble getting to your travel destinations?.....Y**es** **No** **N/A**

Transportation etiquette:

1. Do you use Dial-a-Ride, Access Van?.....Y**es** **No** **N/A**
2. Do you feel safe taking the bus, van, driving?.....Y**es** **No** **N/A**
3. Do you usually arrive and leave on time?.....Y**es** **No** **N/A**
4. Do you know how you should interact with strangers when traveling using public transportation?.....Y**es** **No** **N/A**
5. Do you carry the phone numbers of friends and family when you travel?.....Y**es** **No** **N/A**

GROUPS:

1. HIV+ Support Group.....Y**es** **No**
2. Budgeting Group.....Y**es** **No**
3. RAP Session.....Y**es** **No**
4. Young Gay Men's Group.....Y**es** **No**
5. Transition Group.....Y**es** **No**
6. Young Mother's Group.....Y**es** **No**

Continued on the next page

➢ 5. Transition Assessment — SUNY Downstate HEAT Program, continued

Transition status: _____

Signature of Transition Coordinator: _____

➢ 6. Transition Policy – The PATH Center at the Brooklyn Hospital Center

Subject	Transitioning Services
Policy	▪ **It is the policy of the Brooklyn Hospital Center Family Program to provide transitioning services to youth 21 years of age who have been in care prior to his/her 21st year. New patients who are 21 years of age are referred to the Adult PATH Program for care.**
Procedure	▪ The pediatric-adolescent medical provider will begin to discuss transitioning the adolescent when issues of sex, body image and body changes begin to occur. ▪ Transitioning with females may start when the young woman begins her menses and needs to be referred to the Gyn provider. ▪ **Steps of Transitioning:** **1.** Assessment by the Medical Provider. This includes assessment of the young adult's ability to: name current medications; convey that they are aware of who their provider is and how to reach the provider in case of an emergency; demonstrate a full understanding of their diagnosis and keeping medical appointments. **2.** Patient will then be discussed in multidisciplinary meeting. **3.** Meeting is held with the parent and the young adult. **4.** Several meetings held with pediatric-adolescent CM, Adult CM, and the young adult to discuss issues or concerns the young adult might have about the transition. **5.** Discussion between adult medical provider and pediatric-adolescent medical provider. **6.** Transition decision is made. **7.** Patient is introduced to his/her new adult medical provider. **8.** First appointment made with the new adult provider. ▪ When considering transition, cognitive development, level of maturity, and age-appropriate interventions are always considered. ▪ Patients who have difficulty with the transition can remain in the program and age-out into the adult program at the age of 24. In this case the medical teams from both programs collaborate on the care of the patient. ▪ Young adults in the process of transitioning are also given the option to continue to participate in adolescent activities until they are fully comfortable with the transition to adult care.

Approved: _____Executive Director, PATH Center

_____Director, PATH Center