

# HRSA CARE ACTION



JUNE 2007

Who Is Transitioning?

Managing the Process

Early Rather Than Late

The Independence Factor

## TRANSITIONING FROM ADOLESCENT TO ADULT CARE

"Luisa" is 24 and HIV positive. For the past 6 years, she has been a client at the John H. Stroger Hospital's Division of Adolescent Medicine at the Ruth M. Rothstein CORE Center (AMAC) ([www.corecenter.org](http://www.corecenter.org)), a Ryan White Treatment Modernization Act\* grantee in Chicago.

Luisa has not had an easy life. Between age 9 and 22, she moved from foster home to foster home.<sup>1</sup> Today, in addition to taking care of herself, she is raising her two young children.

"When I arrived at the clinic," Luisa explains, "I had a nasty attitude and I didn't want to listen to anyone, but then I got involved in support groups and decided to get healthy. Because of the CORE Center, I've bettered myself for my kids. I've gotten a lot of advice from my doctor and my case manager and other providers. I've become really attached to my doctor. I like him a lot, and I look up to him and some of my peers."

### DID YOU KNOW?

----- In FY 2005, 11,416 HIV-positive Title IV clients were between ages 13 and 24.<sup>2</sup>

----- Many patients at "adolescent" clinics are no longer adolescents but young adults. The typical age of transition is 25.

----- No standard model exists for transitioning from adolescent to adult care.<sup>3</sup>

\*Formerly called the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act: <http://hab.hrsa.gov/treatmentmodernization>

▶▶▶▶ Please visit our Web site at [www.hrsa.gov](http://www.hrsa.gov)

### ONLINE RESOURCES

Partnership for Family Health,  
*Positive transition to adult health care*  
[www.pffh.org/  
specialinitiatives/ch\\_postran.pdf](http://www.pffh.org/specialinitiatives/ch_postran.pdf)

Georgetown University Center for Child  
and Human Development, Youth and  
Family Perspectives on Transition,  
[www11.georgetown.edu/  
research/gucchd/nccc/  
perspectives/transitions.html](http://www11.georgetown.edu/research/gucchd/nccc/perspectives/transitions.html)

*Transitional care for HIV and AIDS from  
adolescence to adulthood*  
[www.hivguidelines.org/admin/files/  
ce/slide-presentations/  
trans-care.ppt](http://www.hivguidelines.org/admin/files/ce/slide-presentations/trans-care.ppt)

## DIRECTOR'S NOTES

*Leaving familiar people and places is never easy, no matter what age. For young people living with HIV/AIDS, it can be especially hard. An adolescent HIV facility is a safe haven of sorts. For many HIV-positive young people, it is the only place they've ever received care—both the medical kind, and the more human variety that makes us feel loved, protected, and supported. When young people leave this environment, the change they encounter can be monumental. Our job is to make this change manageable.*

*That is no easy task. That is why we've dedicated this issue of HRSA CAREAction to the young adult patient transitioning into adulthood—and into the adult care clinic. Young people speak their own language and have unique pressures and concerns. This issue is an attempt to help us get to know them a little better and to shed light on how we can ensure that they continue to receive care even when the place they receive that care has changed.*

*We believe that you will find the story of Luisa to be a moving one and that this issue of our publication will help you to better serve young patients like her. In doing so, we provide continuity of care for patients—and hope for healthy, productive lives into adulthood and old age.*

*Deborah Parham Hopson  
HRSA Associate Administrator for HIV/AIDS*

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### HRSA CAREAction

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Cover: adolescent in care at a HRSA-funded center. © See Change.  
Page 5: adolescents in care at CORE. Photo by Hal Fuentes.

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At 24 years old, Luisa has reached the age when HIV-positive young people typically transfer to adult care clinics. It's the kind of big change that isn't always easy for an HIV-positive young person.

"I'm not scared of leaving," Luisa says, "and I know I can come back and visit. But it'll be different. I can't open up to everybody and then have them walk out of my life. I've had that my whole life going in and out of foster homes. I've finally found people I trust, and I don't want to start over."

Her sentiments reflect the many needs of a young person who entered the HIV care system needing much more than medical care. Luisa's story is, of course, unique, but it is not dissimilar to that of many of the thousands of young people who will be transitioning to adult care environments in the coming years. Creating a supportive environment for these future adult care clients requires understanding the circumstances surrounding where they come from and who they are.

### Who Is Transitioning?

Transitioning, as it relates to HIV-positive young people moving to adult care settings, can be defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child/adolescent-centered to adult-oriented health care systems."<sup>4</sup> Appropriate transitioning support does not occur automatically, and because young people infected with HIV are now living longer as the result of medical advancements, transitioning is a particularly important issue.<sup>5,6,7</sup>

The vast majority of young people who will be transitioning to adult care sites in the coming years were behaviorally infected with HIV (see the chart on the right). Most are racial and ethnic minorities, and almost all are dealing with the effects of poverty and the lack of private health insurance.

For most of these patients, life has been filled with uncertainty and has been anything but easy. They often come from broken homes with few—if any—resources, including medical resources. In fact, people age 24 and younger

constitute the most uninsured population in the United States.<sup>8</sup> Many youth patients received little or no medical care or access to information about their health prior to becoming HIV positive and entering care at a Ryan White HIV/AIDS Program-funded facility.

Cohorts of HIV-positive people ages 13 to 24 contain high rates of mental illness, homelessness or unstable housing, unstable family life, and severe financial need.<sup>9,10</sup> Many are runaways. With so many problems, their adolescent years can pose a multitude of developmental, security-related, and mental and physical health-related challenges. And these don't necessarily disappear when clients enter adult care.

### Different Times, Different Care Settings

For clients ages 13 to 24 who receive care exclusively at Part D-funded (Title IV) sites, what they find at the adolescent care setting is often unlike anything they have ever encountered. Part D programs are required to address comprehensive client needs. Thus, in addition to doctor's appointments and medications, HIV-positive adolescents and young people encounter encouragement, community, and a safe haven, where they develop close relationships with adults and peers alike. Adolescent service providers function in a quasi-parental role, offering security and guidance to young people who may have been deprived of both of these vital needs.

Examples are the many youth cared for by the Ryan White HIV/AIDS Program who have pursued a college education with the support of their Part D providers. These caregivers take client needs seriously and work with them to achieve their personal goals. Part D-funded sites may provide the following services:

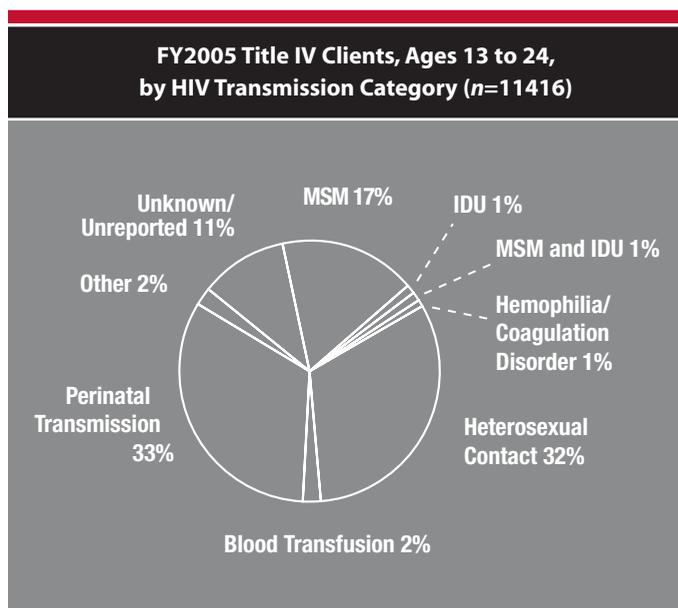
- ▶ Access to comprehensive outpatient medical care
- ▶ Age-appropriate education regarding health, social, and survival issues
- ▶ Mental health care
- ▶ Contact, support, and service delivery from peers
- ▶ Medical and social case management
- ▶ Referrals to social services that are critical to building stability, such as education, housing support, and job training.

This "wrap-around" approach to service delivery is needed to sustain young people with HIV disease whose lives are chaotic and who do not have the financial resources for independent living. Clinical care providers for adults typically receive much less funding with which to provide such services.

Moreover, the higher patient load typical of adult care settings makes it harder to establish personal bonds on which young people may depend. For example, Brooklyn Hospital Center's Program for AIDS Treatment and Health (PATH) Center provides care to children, adolescents, and adults living with HIV/AIDS. According to the Center's 2005 submission for the CARE Act Data Report, the clinic served 96 patients under age 25 in its pediatric and adolescent care division but served 786 people age 25 or older in its adult care division.<sup>11</sup> Higher provider-patient ratios often mean that newly transitioned patients have less face-to-face time with their new providers than they previously had.

Differences like provider-patient ratios and diverse funding streams can create misunderstanding and unease among transitioning patients. Duduzile Zondo-Goins, director of health services at San Francisco's Larkin Street Youth Services (LSYS) explains, "In the adult medical setting, [providers] simply don't have the same amount of time to spend with a patient as [in] the adolescent setting. It's not that adult care team members don't care or are incompetent. But because of what's going through the mind of the young adult patient, it can make them feel inadequately treated.

"It's a matter of perception. The provider may think they've bent over backwards and the young adult patient feels like the provider doesn't care."



Source: Health Resources and Services Administration HIV/AIDS Bureau. 2005. *Ryan White CARE Act data report*.

## THE CORE CENTER OF AMAC



Founded in 1998, the Ruth M. Rothstein CORE Center in Chicago ([www.corecenter.org](http://www.corecenter.org)) is the largest out-patient HIV facility in the Midwest. Its adolescent clinic provides HIV services to approximately 200 people ages 13 to 24. Of the 200 patients served in the adolescent clinic last year,

- ▶ 95 percent were behaviorally infected;
- ▶ Male patients outnumbered females by almost 2 to 1; and
- ▶ 80 percent of clients were African-American, 10 percent were Hispanic, and 8 percent were White.

## Managing the Process

It is not known how often or to what degree transitioning clients face difficulties that threaten health status and functioning, because little evaluation data on the topic exist. What is known is that HIV-positive people, especially the vulnerable populations served through the Ryan White HIV/AIDS Program, face barriers to staying in care that are often extraordinary. Young people do not get a free pass where those barriers are concerned. Leaving a time-tested relationship with a care provider and peers to begin one that can seem full of unknowns may exacerbate the threats posed to health and well-being by these issues.

Therefore, the question for Ryan White HIV/AIDS Program-funded providers is not whether they should be engaged in helping young people transition to adult

care settings. Instead, the question is, what can providers do to ensure a smooth transition and continuity of care for vulnerable young people living with HIV disease?

Although transitioning in the medical system has been studied, little of this research is specific to HIV. Most research on transitioning patients with a chronic disease relates to diabetes, renal disease and, more recently, cystic fibrosis and congenital heart disease.<sup>12</sup> Important points from the general literature are as follows:

- ▶ Discuss transitioning long before it occurs.<sup>13,14,15</sup>
- ▶ Create a transition plan.<sup>16</sup>
- ▶ Encourage and facilitate independence.<sup>17</sup>
- ▶ Have a health care provider supervise transition.<sup>18,19</sup>
- ▶ Deliver chronologically, behaviorally, and developmentally appropriate services.<sup>20</sup>

The literature strongly suggests that providers should work with patients and, when possible, with their parents or guardians, to identify and address the changing needs and expectations of young adulthood and growing up.<sup>21</sup> Preparing young people to transition to adult care also requires that providers “address common concerns of young people, including growth and development, sexuality, mood and other mental health disorders, substance use, and other health-promoting and damaging behaviors.”<sup>22</sup>

Much can be learned from the general literature to help HIV-positive young people transition to adult care, yet the process *must* reflect that HIV disease is unique. Transition occurs in the context of disproportionate rates of socioeconomic problems and comorbidities along with the effects of stigma and taboos. Moreover, many transitioning patients have been behaviorally infected, including 95 percent of clients at AMAC and 97 percent at LSYS. A successful transition for HIV-positive young people must take these issues into consideration.

## Early Rather Than Late

Because adolescence and young adulthood involve developmental changes in physical, psychological, and social areas, transitioning to adult care ideally takes place during a stable time when patients are chronologically

as well as behaviorally and psychologically ready.<sup>23</sup> Achieving readiness is not a simple process.

For youth transitioning to an adult care clinic, Chicago's AMAC, where 24-year-old Luisa receives HIV services, would appear to hold at least two advantages. In addition to a long tradition of successfully delivering culturally competent and comprehensive services to young people, the CORE Center's adolescent and adult care clinics are housed in the same building, and a nurse practitioner on staff divides her time equally between the two clinics. This approach helps ensure a seamless transition that avoids any gaps in services.

However, according to Hal Fuentes, primary care coordinator for adolescent medicine and a psychologist at AMAC's clinic, "Almost all of my clients transitioning to adult care initially express apprehension, anxiety, and discontent. The initial reaction is [that transition] isn't what they want."

AMAC addresses transition proactively. "We begin discussing transition with patients at least a year before they make the physical transition," says Fuentes. "Our patients getting ready for transition have the opportunity to come talk to me," he explains, "and if they need to process, they can. In some cases, especially for patients with mental health issues, we start the process [6 months] to 2 years prior to the actual transition date."

At LSYS in San Francisco, the process starts much earlier. LSYS targets people who are among the most vulnerable in society—teenagers and young people with histories of homelessness. Many clients also are coping with poor education, unemployment, and estrangement from families. The role of LSYS is to help their clients first find housing, and then address issues related to education, employment, and health care. Ultimately, LSYS provides a comprehensive approach to the multitude of problems faced by its clients and to create stability where there has previously been none.

"The first day they come in, we begin preparing them for transition to adult care," says Zondo-Goins. She

has seen firsthand the difficulties that young people face during this period.

"Twenty-five-year-olds are going straight from being called 'youth' to facing the challenge of being fully integrated into an adult world," she explains. "The care system sometimes assumes that by age 25, you're a fully functioning adult, but in some cases that's simply not true."

The question of when to begin transition has no definite answer. Patient needs differ and help determine when the transition process begins. For patients like those at LSYS, if basic housing needs go unmet, the likelihood of health maintenance is greatly compromised. In such cases, transitioning may have to start *after* other needs are addressed.

## The Independence Factor

When it comes to transition, some young patients may feel all grown up and ready to be self-sufficient. In other ways, they may still need many of the supports they received in adolescence. This situation can be especially true for the historically underserved Ryan White HIV/AIDS Program clients, who often cope with medical and socioeconomic challenges on several fronts.

Young people may develop conflicting feelings about transitioning. They may be ambivalent toward a health care setting in which they are the oldest patient, or they may be hesitant to leave the care unit with which they are familiar.<sup>24</sup> Their apprehension may have to do with developmental issues. For patients like Luisa, the care community may be like a family—the only one they feel is real.

In these situations, it is easy to understand why HIV-positive people may struggle with ending relationships with adolescent providers.<sup>25,26</sup> And, like their adolescent patients, providers also struggle with saying goodbye. If unaddressed, feelings on both sides of the care relationship may pose a barrier to successful transition.<sup>27,28</sup>

## LARKIN STREET YOUTH SERVICES

The organization known today as Larkin Street Youth Services ([www.larkinstreetyouth.org](http://www.larkinstreetyouth.org)) began in 1984 to help San Francisco's homeless youth get off the street. Its HIV program, started 13 years later, made LSYS the Nation's first comprehensive housing program for HIV-positive youth. LSYS helps its clients find subsidized housing; it also provides medical services, including HIV care, prevention, and outreach; education; meals; mental health and substance abuse services; and hygiene products. LSYS serves 90 HIV-positive clients who range in age from 18 to 24. About 72 percent are male, and 97 percent were behaviorally infected.

The literature also cautions, “Many [young adults] with chronic conditions are at higher risk than peers for unnecessary dependency, developmental difficulties, and psychosocial delay.”<sup>29</sup> And families and providers can sometimes “shelter or overprotect” young adults with a chronic illness, which can make it even more difficult to gain autonomy.<sup>30</sup>

To help youth navigate the adult health care setting, they must have an environment in which they can work through their fears and anxieties. In addition, “[they] must be permitted and at times encouraged to take an increasingly more active role in their health care.”<sup>31</sup> New responsibilities may include the following tasks:

- ▶ Self-management
- ▶ Scheduling appointments
- ▶ Refilling medications
- ▶ Identifying a support system
- ▶ Finding transportation
- ▶ Discussing education and vocation goals
- ▶ Participating in the application process for available health or income assistance, and
- ▶ Acknowledging obstacles to care.<sup>32,33,34</sup>

## Unfamiliar Environment, Unfamiliar Feelings

Adolescent and adult care are provided in very different physical environments. The adult care setting typically has a more diverse client base and may bring newly transitioning young adults into contact with people whose age, culture, and other characteristics may make them uncomfortable.

Transitioning patients are moving from care settings in which they often are among the oldest clients to those in which they may be the youngest. The change can create a “culture shock”—a sense of not fitting in.

The new setting also can make young people more conscious of their own mortality, particularly for those who were perinatally infected and have already lost one or both parents. In an article devoted to transitioning patients in the United Kingdom, a young patient is described explaining “how being in an adult HIV setting would force him to confront the inevitable growing older with HIV, knowing well that the older he got, the longer he would have HIV and the higher the chance of developing illness.”<sup>35</sup>

## New Providers, New Relationships

With a new clinic comes new relationships—and the challenge of learning to trust all over again. Transitioning

clients may be afraid to confide in a new provider, fearing that the provider may disclose information to their parents or condemn the clients’ behaviors.<sup>36,37</sup> Those challenges must be overcome, because developing a trusting and respectful relationship with transitional young adults is pivotal in improving their health.<sup>38</sup>

One solution is for providers to adopt a nonjudgmental attitude and create an open communication process. Research shows that chronically ill young adults are unlikely to raise questions that a health professional might condemn. Thus, a nonjudgmental approach may reduce the chances that the patient will lie about treatment adherence.<sup>39</sup> This approach also may help young adult patients feel like respected members of the treatment team, something many young adults say is lacking in their relationship with their adult care provider.<sup>40</sup> “Talk to kids and make them feel like unique individuals. Listen to what they have to say,” advises Zondo-Goins.

Talking to young adult patients, however, is only part of the solution. Adult health care staff also may have limited understanding of the developmental, cultural, or psychosocial issues of this age group.<sup>41</sup> Many adult care providers have acquired cultural competency for serving minorities, men who have sex with men, transgendered patients, women, substance abusers, and other populations. The same cultural competency is needed to serve transitioning patients.

## Building—and Crossing—a Bridge

The success of providers during the transitioning period may affect clients’ health status and functioning. Success also may improve the quest to keep people in care over time, and it may reduce the number of HIV-positive people who know their status but are not in care. Organizations like AMAC and LSYS offer practical guidance to providers seeking to enhance their transitioning capacity. Their approaches, summarized on the right, reflect the challenges of different client bases.

The entry of young adults into the world of adult HIV care also warrants further study because when it comes to transitioning, young adults are asked to do far more than seek care at another clinic. Many are leaving friends and a kind of sanctuary. The care facility may be the one place where they feel comfortable being themselves, where their worries are kept confidential, and their well-being is of genuine concern to their caregivers. For homeless youth at LSYS, adolescent care means having a warm meal, clean clothes, and a safe place to sleep. And for people like Luisa, it means having a sense of family after moving from foster home to foster home.

## TRANSITIONING AT AMAC

To build a bridge for transitioning young clients:

- ▶ AMAC forms a multidisciplinary team, including a psychologist, social worker, nurse, and medical provider.
- ▶ The point person who oversees the transition is a nurse practitioner who spends equal time with adolescents and adults.
- ▶ One to 2 years prior to transition, AMAC begins preparing clients for it.
- ▶ Adolescent care providers partner with adult care staff to ensure a welcoming and supportive environment in the new care setting.

Through in-house partnerships between adult and adolescent providers, AMAC addresses a major issue, namely, the capabilities of adult care providers to treat transitioning youth.<sup>42</sup> The following may be a guide for providers when referring young adults to an outside agency for medical support:

- ▶ Assess the agency's philosophy: Are staff friendly toward youth? Do they understand all the developmental and cultural issues?
- ▶ Offer training to agency staff to improve capacity to serve young adults.
- ▶ Listen to agency concerns and work with them to create solutions.
- ▶ Find out who will be accountable for the transitioning client.
- ▶ Invite adult provider staff, especially case managers, to participate in adolescent provider staff meetings, and vice versa.
- ▶ Together, explore whether the client is ready for transition and who in the adult facility is best suited to work with him or her.

## THE LSYS APPROACH

LSYS is a community-based organization addressing the many needs of youth with histories of homelessness. Some clients have not known about their HIV status for long, and are dealing with fears of mortality. They have also had to deal with instability, trauma, and estrangement from family. These factors shape the LSYS approach.

- ▶ To help create stability in the client's life, transitioning starts the day the client arrives. Stability is a vital step in preparing for adult care.
- ▶ Transitioning is collaborative. Clients are asked to identify what they want to achieve at LSYS and where they want to be when they leave.
- ▶ The client works with a case manager and a peer advocate to create an individual service plan. Progress toward the plan is tracked.
- ▶ To foster a sense of security, peer advocates initially accompany LSYS clients to medical appointments. Once clients feel more confident, they are encouraged to go to appointments alone.
- ▶ Clients are encouraged to access services from community organizations that partner with LSYS. Even when the same services are offered at LSYS, this approach helps build a bridge to adult care.

Because transitioning is never easy, young patients need to be as prepared as they possibly can, and providers need to know how to help them. As Zondo-Goins puts it, "foster independence, encourage, and empower" young people to thrive in the adult care setting.

In addition to preparing patients for transition, providers must prepare themselves. They must do so in the context of limited time to spend with patients and limited funding for support services that patients may need.

Providers like AMAC and LSYS demonstrate that success depends on an open, accepting environment for young people and that adult care providers must bring that same openness and acceptance to a generation of people whom they may not understand. Just as patients may go through culture shock when entering the world of adult medicine, adult care providers may experience their own culture shock when encountering patients who grew up in the 1990s. Providers may be exposed to a way of communicating that they do not understand and to behavioral norms that are distinctly not their own.

Alongside those challenges is the test of treating patients at an age when many are rebellious, feel invincible, and are trying to figure out how to survive in the adult world. Any of those issues would pose an obstacle—together they pose a formidable challenge.

Caring for transitioning patients is a difficult enterprise. It demands the same quest for capacity that has helped providers meet the needs of other HIV-positive subpopulations. How well providers acquire this capacity will be reflected in the proportion of young people who successfully cross over to adult care and who stay in care on the new side of the transition bridge. ◀▶

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