

Camp Sunrise and The Ohio AIDS Coalition Present:
TRANSITIONING HIV POSITIVE YOUTH INTO ADULT CARE

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Foreword

Every year nearly 5,000 new HIV infections every year occur among young people under 25 years of age. HIV infection in youth aged 13-24 represented more than 13% of all new cases reported nationally in 2007 (CDC, 2009). Most new HIV transmission cases among young people are based on behavioral risk such as unprotected sex or sharing needles. However, 100-200 new cases of HIV are among perinatally infected infants, children who acquired HIV through mother-to-child transmission. HIV transmission from mother-to-child during pregnancy, labor and delivery, or breast-feeding has dramatically declined since research published in 1994 demonstrated that zidovudine (ZDU) given to pregnant women infected with HIV reduced perinatal transmission. Identification and education of pregnant mothers along with timely intervention of antiretroviral therapy during pregnancy has led to this decline in perinatal transmission. Still, perinatal transmission is the most common route of HIV infection in children and is the source of almost all AIDS cases in children (CDC, 2009). In 2007, 142 children less than 13 years old received a diagnosis of HIV or AIDS from perinatal infection (CDC, 2009).

While more than half of young people born with HIV since the beginning of the epidemic have died (57%), an estimated 6,051 persons

who had been infected with HIV perinatally were living with HIV/AIDS at the end of 2005. Many of the teens and young adults born perinatally infected in the 1980s and 90s are now reaching adulthood. Thanks to medical advances in the treatment of HIV/AIDS, HIV positive youth, both perinatally and behaviorally infected are living longer. Young people who received an AIDS diagnosis from 1996-2004 lived longer than any other age group except those younger than 13 years. According to the Centers for Disease Control, nine years after receiving an AIDS diagnosis, 76% of those 13-24 and 81% of those younger than age 13 were still living. Instead of assisting young people and their families with planning for end-of-life care and terminal AIDS, more providers and counselors are working with youth and their families with future planning, goal setting and transitioning into adult medical care.

Transitioning youth clients into adult care can bring many challenges for youth and their families. With foresight and proper planning, providers can help minimize the negative impacts of care transition and increase the probabilities that HIV positive clients are retained in HIV care and treatment. Retaining young adult clients in care and treatment can be crucial to their long-term prognosis, to slow disease progression and assist HIV positive clients in their secondary prevention efforts through viral load management and other secondary HIV prevention strategies. Without

proper transition planning, HIV positive youth may experience severe anxiety and other psychosocial issues, including feelings of abandonment and neglect—particularly if they have lost their parents or primary care giver(s) through an AIDS-related death. For HIV positive youth who have accessed services in a nurturing and supportive adolescent care setting for years, clinicians and social service workers can be more than providers for youth, they can become surrogate or extended family. Transition can feel like yet another loss in the life of a young person whose journey has chronically been challenged with grief and loss. Providers in adolescent settings can also be responsible for compounding the psychological challenges that may accompany client separation from adolescent care based on the providers' own emotional attachments to youth clients, by “coddling” clients at a time when systematic emotional and practical preparation for transition is essential to a successful client transition into adult care. Many of those in early to mid-adolescence were diagnosed to have HIV before effective HIV treatment was available and initially were not expected to survive beyond early childhood. This has resulted in a tendency for families and services to shelter and overprotect these children adding strain to the adolescent processes of independence, autonomy, and self-esteem (Lyall, 2007). Clients need supportive partners and environments that strategically encourage transition to help clients best negotiate what can be a disruptive

moment in their continuum of care, if not properly managed.

Though there is no national data identifying the number of young adults who leave care during this transition, anecdotal evidence suggest that some youth will drop out of care if there is not a transitional process attentive to youth psycho-social needs. Leaving the nurturing confines of youth-centered care and support settings can be an unsettling and traumatic event for young clients with good reason. Long-term survivors transitioning out of youth-centered medical care into adult care often find there are far fewer supports for HIV positive clients in adult care than what youth experienced in an adolescent-centered clinical setting. While sensitive to their client needs, adult clinical settings rarely have the time, nor are they generally oriented to provide the level of client advocacy, mitigation and “hand-holding” youth clients have become accustomed to in youth-oriented clinical environments. In adult care, youth clients are treated as adults and are expected to attend to their clinical and therapeutic support needs in a mature and responsible manner, sometimes long before such behaviors and capacities have manifested themselves in the client.

As one issue brief noted, practitioners may feel they are “bending over backwards” to provide quality care to the youth client, while the client may feel providers in their new, more formal environment are insensitive to their needs and

“don’t care about them.” Management of youth expectations and provider education of transitional issues, adolescent development and capacities, and the unique care needs and concerns of young adult clients are essential ingredients for effective transition. Bridging the disconnect between youth expectations as consumers accessing an adult clinical setting and those of adult-centered practitioners offering services in those settings can be done through proper transition planning by clinical and social service practitioners while clients are still accessing services in the adolescent setting. Though the establishment of science-based models for proper transitioning of youth clients into adult care is still in its infancy, organizations throughout the country have already begun to individually establish effective models and best practices for addressing this growing need.

While generally sharing common core elements in their planning activities, organizations known to have efficiently transitioned youth to care vary in matters of age of transition and strategies for practical implementation.

Organizations take different approaches to addressing the transition needs of youth, based on: the agency-type (i.e., camps, clinic-based, etc.), characteristics of the target youth population (i.e., homeless, etc.), frequency of interaction with youth (i.e., seasonal, weekly, etc.), access to resources in the community, and the depth of the agency’s relationship with adult clinical providers—those partners willing

to engage in a collaborative process for client transition.

With the exception of a few government issue briefs and researcher presentations at national medical and public health conferences, providers’ various approaches and practices have rarely, if ever been compiled and made broadly available in a form useful for consideration by program planners and service providers transitioning youth to adult care. Scientific research, particularly on the domestically, has also failed to keep pace with the informational needs of those adult providers confronted with ever growing caseloads of young clients. As thousands of HIV positive adolescents’ age out of pediatric care and transition into adult care, there has been a scramble to provide services that effectively accompany clients into adulthood. In this reactionary environment, there has been minimal effort to provide practitioners with a baseline understanding of HIV positive youth that is sensitive to the population’s variances in status, identities, and programmatic needs.

As an initial step toward meeting this knowledge gap, the Ohio AIDS Coalition and Camp Sunrise have contracted researchers at Faithwalk Enterprises, LLC to: identify those organizations effectively transitioning youth into adult primary care and support services, conduct a literature review to determine what information is available about the unique needs of HIV positive youth clients transitioning into

care, and to offer guidance to those practitioners seeking to initiate or improve transition planning at their agencies.

This manual is the result of six months of data review and analysis and represents the best of the domestic information available today for service providers. The document is divided into three components: a literature review that explains the issues and identifies trends in the research findings, a presentation of organizational best practices and procedures, and discussion guidance for providers seeking to assist a youth in developing and successfully completing a transition plan.

In an effort not to reinvent the wheel, occasionally tables and narrative information are directly replicated from the source material and appropriately cited as such. This is particularly true under the entitlement section descriptions of federal programs, benefits, and access points. However, this document primarily represents a synthesis of information from several sources, including: peer review journals, fact sheets, issue briefs, clinical procedural guidance, agency quality assurance plans, and research presentations from noted experts in the field of pediatric HIV. For now, this document is the most comprehensive overview available of the field's current understanding of how to successfully transition young HIV positive clients into adult care. It is our hope that the enclosed examples of expert and organizational best practices and

programmatic considerations will inspire thoughtful review of your current practices and the development of homegrown models for maintaining the continuum of care for HIV positive young people in a variety of settings, regardless of geography. In the end, the goal is for practitioners and organizations to cultivate the essential supports and environments that engender youth to achieve their best possible health outcomes.

Executive Summary

Transitioning HIV positive youth into adult care is a tricky business, though one with simple, if labor intensive and time-sensitive solutions. Engagement in youth transitioning into adult services is no longer an act that can be haphazardly done without clear planning and intentional execution. The number of HIV positive young people entering adulthood is too high. Even long-term survivors of perinatal HIV infection are living longer and beginning to consider a future experiencing HIV as a manageable, chronic condition. Historically managing long-term client expectations and preparing youth for short-term prognosis of death and disease, youth serving agencies must now prepare HIV positive young people for living and self-sufficiency.

Fostering resiliency and self-sufficiency requires planning and guided case management in gradual stages. It requires calibrating client and staff expectations along a collaborative journey and highly coordinated partnerships between youth and adult serving agencies (or divisions in the case of large clinical institutions) that can offer seamless transitions into adult care for young people still developing into maturity, both physically and psychologically. It also means addressing youth holistically, to instill the necessary protective

factors and life skills that will ease youths' transition not just into adult care, but into adulthood. Addressing a youth client's HIV needs exclusively from a pediatric care perspective is no longer sufficient. These fresh challenges and opportunities for sustainable adolescent care require clinicians and other youth stakeholders to cultivate an intentional, monitored process for youth that is as diverse as the youth themselves.

While there are similarities among HIV youth, each case represents a special challenge and opportunity for service provision. Young people who are behaviorally infected present different obstacles and experiences than those who are perinatally infected. Although the majority of HIV positive young people accessing non-profit health care and supportive services are typically uninsured racial, ethnic and/or sexual minorities and generally derive from resource-deprived communities, HIV positive youth still widely vary as much by sex, class, sexuality, gender expression, culture, and experience as they do by any other significant cultural markers. Client age and developmental stage must also be contended with when clinicians and agencies are designing individual plans for transitioning youth, with action steps reflective of the cognitive capacities and readiness of the individual client. This broad diversity means that a "one-size fits all" approach or strategy will prove insufficient for most young people and that individualized, client-centered approaches self-directed by

independent clients of ever-burgeoning autonomy prove the most effective strategy for moving youth from adolescent to adult care.

There are core goals and outcomes desired by all agencies that work with transitioning youth. A young person successfully transitioned into adult care has at a minimum the ability to achieve the following skills:

- Self-management
- Schedule appointments
- Refill medications
- Identify a support system
- Find transportation
- Discuss education and vocation goals
- Participate in the application process for available health or income assistance
- Acknowledge and negotiate obstacles to care

The lifeskills needed by HIV positive young people after having transitioned are to:

- Know when to seek medical care for symptoms or emergencies
- Be able to identify one's symptoms and describe them
- Use one's primary care provider appropriately
- Make, cancel, and reschedule appointments
- Come to appointments on time

- Call ahead of time for urgent visits
- Request prescription refills correctly and allowing enough time for them to be refilled before needed
- Negotiate multiple providers and subspecialty visits
- Understand the importance of healthcare insurance and how to get it
- Understand entitlements and knowing where to go for each
- Establish a solid relationship with a new case manager

Agencies successful at transitioning youth into adult care offer:

- Flexible service hours, including weekends and evenings
- Walk-in appointments
- Are public transportation accessible, transportation or fare cards offered
- Intensive case management with strong referral mechanisms
- Incorporate youth involvement
- Cosmetically establish a youth oriented environment, with resources and environmental markers specific to the youth population served
- Make materials available in the languages and literacy levels of the youth served.
- Help young people adjust to their HIV status

- Provide a continuum of care either directly or through referrals with other youth friendly agencies

This tool aims to provide a wide range of service considerations, models, and best practices, and science-based subject matters pertinent to quality service provision.

Key steps for establishing organizational partnerships between youth and adult service agencies or divisions, recommendations for avoiding common pitfalls, and several examples of case worker youth transition plans are also included in this manual.

EFFECTIVE PROGRAMS MANAGE HIV TRANSITION PROCESSES BY:

- Maintaining an asset- or strength-based in approach
- Being age and developmentally appropriate
- Being client-centered and sensitive to client readiness
- Discussing transitions early
- Creating transition plans
- Creating a plan to meet transitional issues of pregnancy and motherhood
- Being as chronologically flexible as possible in applying agency transitional guidance (i.e., client-centered)
- Encouraging and facilitating independence among youth
- Having a health care provider supervise transitions, preferably supervising a multi-disciplinary team
- Addressing young people's knowledge of both their HIV status and sexual health issues, creating secondary prevention plan and documenting progress with plan adherence
- Conducting personal provider self-checks to ensure the provider attachment is not the barrier to transition
- Partnering with parents or caregivers, when possible, to ensure coordination of "letting go" by caregivers
- Progressively moving clients through transitional benchmarks related to increasing responsibilities & autonomy
- Offering, as possible, a multi-disciplinary team approach to youth care during transitional years
- Fostering youth inclusion in health care discussions and eventually in clinical decision making
- Recognizing the individual needs, abilities, experiences, beliefs, and expectations
- Respecting and accommodating the cultural views and sexual diversity of clients
- Providing an open, non-judgmental environment where youth can work through their fears and anxieties and articulate expectations
- Ensuring simultaneous transition of mental health and case management with transition of primary care
- Defining, documenting and reviewing outcome measures and success indicators throughout the process
- Offering multi-disciplinary training for adult providers in dealing with long-term survivors of perinatal HIV

- When necessary, build the capacity of adult providers through training and technical assistance follow-up to ensure collaborative partnership and uninterrupted continuum of care for the client
- Has trained staff familiar with practical application of adolescent development theory in care and service
- When possible, provides a detailed medical and social history of childhood illnesses (including information the youth may have been too young to remember), discussions, and social concerns in a detailed summary to the adult provider

Issues Facing Youth Transition Into Adult Care: A Literature Review

INTRODUCTION

The following is an introduction to the scientific literature on HIV positive youth in addition to some qualitative research conducted by Faithwalk Enterprises, LLC in an effort to define the scope and scale of the issues facing HIV positive youth transitioning into adult care and the providers servicing these most vulnerable clients. Methods for conducting this review included:

- A limited assessment through qualitative surveys sampling 30 providers with HIV prevention transition programs for youth clients;
- Key informant interviews;
- Expert interviews;
- And a review of peer review journal articles, national databases, fact sheets, issue briefs and white papers.

The sum of this research is presented in this chapter by issue area and written with the goal of broad accessibility by practitioners, clients,

and youth stakeholders concerned with the relevance and quality of care available for HIV positive youth. This review, while comprehensive, is by no means exhaustive. It is recommended that the results of this review should primarily be used with the purpose of informing organizational discussions of these matters and to inform program design and planning for service accessibility and delivery for HIV positive teens and young adults.

RESEARCH LIMITATIONS

Domestic research on HIV positive youth is a patchwork quilt at best, one with too many holes. While there is research on perinatal and behavioral youth acquisition of HIV, the spotlight tends to be on primary prevention, helping to prevent mother-to-child transmission or further preventing transmission to uninfected individuals, rather than on care or service delivery for those youth who are already infected. When the needs and issues of HIV positive youth are discussed, they rarely distinguish those youth who are perinatally infected from those who behaviorally acquired HIV, choosing instead to broadly discuss HIV positive youth as a single population. Though perinatally and behaviorally infected youth have many commonalities, there are substantive differences among the sub-groups and populations comprising the HIV positive youth population. Trend differences related to life expectancy, quality of life, self-care and mental health, and acquisition of co-morbidities or infections are just some of the variables that

may differ among youth clients, depending on the age of diagnosis, route of transmission, and age to transition into adult care. HIV positive youth have other variables research too often fails to consider when discussing them in the literature, including the gender identity, sexual orientation, racial and cultural heritage of HIV positive youth. Even the age of a young person with HIV can dramatically determine client capacities. These identifying characteristics remind us that HIV positive youth are not a monolithic group, and should not be treated as one. Though some sexual minorities and racial and ethnic groups are disproportionately represented among HIV positive youth, the HIV positive youth population is as diverse as the general population, with just as many variances in needs, issues, and concerns.

The research on HIV positive youth also tends to be focused on parent-child communication of an HIV diagnosis, end-of-life care, and permanency planning for HIV positive parents of youth. While extremely helpful in assisting families with issues of disclosure, bereavement, medical and legal concerns related to terminal illness it implies that many HIV positive young people still reside in a family context, with supportive care givers. The care of young people who have lost one or both parents to HIV is not always assumed by blood relatives and kinship networks; some orphaned HIV positive youth end up living in the foster care system. With the majority of new HIV infections for those under age 25 occurring

among young men who have sex with men (YMSM), particularly YMSMs of color, there are additional social stigmas of homophobia both within the family context and by service providers to contend with. Further, gay and bisexual young men are disproportionately displaced from their homes and families following disclosure of their sexual orientation, which can be a facilitating factor in their HIV acquisition or can precipitate them losing their housing and family ties. Providers working with HIV positive youth of legal age, those 18 and older, may find sustainable housing difficult to identify for YMSM based on a reluctance of landlords willing to provide housing for teens and young adults. Housing barriers based on ageism, racism, and homophobia may persist even for those youth clients eligible for housing resources under Housing Opportunities for People Living with AIDS (HOPWA). Residing in foster care or struggling with issues of homelessness based on sexual orientation has implications for practitioners and their approach to effectively servicing clients. The absence of these issues in the literature is troubling and needs further study to help providers better meet clients' needs.

Still, there is information available about HIV positive youth in general that may prove useful in educating adult practitioners unexposed to unique adolescent and young adult challenges or looking for insight into how to adequately address their needs. Additionally, research on

both general youth development and adult HIV positive individuals also can offer service providers useful bridges that cross into the concerns of HIV positive youth, issues that may require further youth and practitioner education and mutual problem solving. It is our hope that this data synthesis will provide clear information and possible first steps for providers servicing this population.

UNDERSTANDING THE HEALTH NEEDS OF HIV POSITIVE YOUTH

An estimated 35,000 U.S. teenagers now have HIV/AIDS. Far more have been diagnosed with HIV, and an undetermined number have the virus and do not yet know (Lyon, 2006). According to Advocates for Youth, after receiving a positive diagnosis of HIV infection, youth need answers to questions about their illness (Advocates for Youth, 2008). Positive Life, another resource for HIV positive youth, also states that recently diagnosed teens need information on HIV geared to youth (PositiveLife.net, 2005). In response to the information needs of “just diagnosed” HIV positive youth, Advocates for Youth and Positive Life have created web pages designed to answer some of the questions HIV positive youth may have. Studies conducted to determine the efficacy of HIV/AIDS information for today’s youth indicated that the internet is a viable method of disseminating information to HIV positive youth.

LIVING WITH HIV/AIDS

Although the numbers of HIV positive youth continues to increase, finding and engaging youth in treatment programs has proven to be challenging. A study conducted by Dr. D.N. Bell claims that HIV-positive adolescents will constitutionally remain a “hidden population,” and a great deal of time and effort will continue to be needed to go into the front end of outreach, counseling and testing (Bell, 2003). In research conducted by Dr. Mary Jane Rotheram-Borus a variety of delivery strategies were discussed for secondary interventions for youth living with HIV. Rotheram-Borus’ research describes an intervention program for youth living with HIV that was delivered in 30 sessions with three modules (Rotheram-Borus et al, 1998). A study of Boston Happens, a program designed for HIV positive youth outreach, indicates that outreach, mental health, and case management services can improve retention of HIV positive youth in long-term treatment programs (Harris, 2003). Duplicating the work of Rotheram-Borus, Dr. Marguerita Lightfoot holds that secondary prevention programs are needed to help youth living with HIV meet three goals: (a) increase self-care behaviors, medical adherence, and health-related interactions; (b) reduce transmission acts; and (c) enhance their quality of life (Lightfoot, 2007). Research on youth living with HIV cites that identifying HIV positive youth and getting them into treatment programs as *the* major obstacle to the long-term health outcomes of HIV positive youth.

UNIQUE CHARACTERISTICS OF VERTICALLY AND BEHAVIORALLY ACQUIRED HIV

There are two subgroups of HIV positive youth, those who acquired HIV perinatally (also known as vertical or mother-to-child transmission) and those who acquired HIV behaviorally. According to Dr. Jeffery M. Birnbaum of SUNY Downstate Medical Center, these two epidemiological sub-populations

share and differ in ways that have implications for service delivery and program design. As our amended comparison chart of Dr. Birnbaum's list (Birnbaum, 2008) will demonstrate, despite advances and longer term prognosis for perinatally infected youth transitioning into adulthood (advances made possible since the advent of antiretroviral therapies), perinatally infected youth have poorer longer-term health outcomes than behaviorally infected youth.

PERINATALLY INFECTED YOUTH	BEHAVIORALLY INFECTED YOUTH
More recent growth in size of this epidemiological cohort; will attenuate in next 10-15 years	More likely to be in earlier stages of HIV disease
More likely to be in more advanced stages of HIV disease and immunosuppression	Less opportunistic infection complications
More likely to have experienced a high number of opportunistic infections with complications/disabilities (e.g. blindness, chronic renal failure)	No previous antiretroviral exposure less likely to be resistant to antiretroviral
More likely to have heavy anti-retroviral exposure in high numbers and is therefore more likely to have multi-drug resistant virus	Less likely to require HAART and when HAART required, it can be given in simpler regimens
More likely to require HAART to control viremia, low CD4 counts	Treatment adherence problems may be relatively simpler to manage than perinatal group
More likely to have complicated anti-retroviral regimens (e.g. "mega-HAART")	More likely to achieve functional autonomy
More likely to have complicated non-anti-retroviral medications such as opportunistic infection prophylaxis/treatment	Less likely to have complicated non-anti-retroviral medications such as opportunistic infection prophylaxis Perhaps more likely to acquire a co-morbidity such as an STI or hepatitis
Greater obstacles to achieving functional autonomy due to physical and developmental disabilities/greater dependency on family (e.g. "adult" vulnerable child)	Less likely to experience challenges with autonomy, less likely to have physical and developmental disabilities, more like to be estranged from family based on HIV stigma and/or sexuality concerns
When pregnant, higher risk of complications during more advanced stages of disease and of second generation HIV transmission due to multiple-drug resistance	Less issue of second generation HIV transmission in pregnancy if HIV acquired was not from a long-time survivor or other carriers more likely to have a drug resistant strain
Higher mortality rates than behaviorally infected youth	Long-term chronic disease outlook

Table adapted from Dr. J.M. Birnbaum's ppt. *Transitional Care For HIV/AIDS from Adolescence to Adulthood*

Dr. Lawrence B. Friedman, Director of the Division of Adolescent Medicine at the Miller School of Medicine in the University of Miami, identified several other psychosocial factors of perinatally infected and behaviorally youth,

including factors related to prolonged survival and behavior. The following table offers a list of the different challenges experienced by these different sets of youth (Friedman, 2007), but does not reflect a direct comparison:

PERINATALLY INFECTED YOUTH	BEHAVIORALLY INFECTED YOUTH
Increased incidence of cognitive diseases such as: learning disabilities, speech problems, and loss of IQ	Has a different experience with disease based on timing of infection and personal role in risk taking
Attention Deficit Disorder (ADD) leading to poor attention span, difficulties concentrating, school failure, and hyperactivity	Early intervention may preserve immunity and good health
May not know their own diagnosis or HIV status may have been disclosed at a later age	May experience more challenges to treatment adherence
More likely to have experienced multiple losses related to HIV and AIDS (parents, siblings, etc.)	More likely to have denial and fear of HIV status
Issues with prolonged secrecy regarding disclosure	More likely to have misinformation about HIV and personal risk for HIV
Struggling with issues of evolving sexual awareness and sexual identity as a positive youth,	May have a distrust of the medical establishment
Have heightened concerns about pregnancy and childbearing	Fear or lack belief in effectiveness of medicinal treatment
Problems with adherence and rebellion	Higher rates of low self-esteem, depression and anxiety
Legal concerns regarding HIV status and disclosure	Unstructured and chaotic lifestyle, requiring more time, energy and effort by providers
More likely to experience challenges to autonomy from family and long-term practitioners in an effort to establish independence.	More likely to lack familial and social supports

Table adapted from a presentation of Dr. Lawrence Friedman, *Movin Out: Transitioning Model for HIV Infected Adolescents Entering Into Adult Care*.

DISPARITIES IN HEALTHCARE

Studies continue to document that youth with human immunodeficiency virus (HIV) experience discrimination in their interactions with the health-care system, which can have

negative implications for maintaining continuity in care and in youth outcomes (Sohler, 2007). Perceived stigma in clinical settings may discourage HIV-infected individuals from accessing needed healthcare

services (Kinsler, 2007). A commentary on the disparities experienced by HIV positive youth notes that the majority of youth programs are designed for adults and that HIV positive youth reject programs not designed for them (Lyon, 2003). Research findings indicate that stigma associated with a positive HIV status, and programs designed for adults create barriers to healthcare for disadvantaged HIV positive youth.

PHYSICIAN REFERRALS

For many HIV positive youth, receiving medical referrals to physicians does not occur. Some newly diagnosed youth enter into a period of denial for almost six months after receiving a HIV positive test result (CDC, 2008). Youth-sensitive testing programs designed to offer immediate counseling and mental health services for the newly diagnosed have been able to successfully transition more HIV positive youth into treatment programs than those that fail to offer agency supported referrals (Bay Positives, 2008). Many HIV positive youth are experiencing an illness for the first time in their lives and have little sense of how to navigate these medical and mental health systems. These youth require assistance with accessing services ranging from physician referrals to proper instructions and supports for taking their medications on a consistent schedule (YouthCare, 2008). All of the cited research articles on HIV positive youth indicate that HIV positive youth will need assistance navigating the American healthcare system.

Programs that are developed for HIV positive youth will need to train them to understand healthcare. Examples of these programs can be found in the subsequent best practices section of this toolkit.

HEALTHCARE RIGHTS AND RESPONSIBILITIES

HIPAA is an acronym that stands for the "Health Insurance Portability and Accountability Act of 1996" (Beaver, 2004). HIPAA enacts rules and regulations that protect the confidentiality of individual's health information (Biel-Cunningham 2003). HIV positive youth are uniquely vulnerable to breaches of confidentiality because of their status as dependent minors (Gudeman, 2003). Ensuring privacy maintenance of HIV positive youth's information and disclosures can profoundly influence youth decisions to address their health needs and to maintain their enrollment in treatment programs (Romero, 2007). In a 2004 position paper, the Society for Adolescent Medicine stated that investigation is needed on ways that health professionals can encourage HIV positive youth to communicate their health care status to their parents (Ford, 2004). A program at the University of Alabama has designed youth-friendly HIPAA information to address the privacy issues concerning HIV positive youth. Research has shown that not protecting the privacy of HIV positive youth discourages them from seeking care and is a violation of federal law.

LEARNING TO BE ASSERTIVE

Youth who are not perinatally infected became infected due to high-risk behaviors (CDC, 2008). High-risk behaviors that lead to HIV infection in youth have been correlated to low levels of assertiveness in youth who became HIV positive (Padilla-Walker, 2008).

Adolescents are frequently admonished to be socially assertive in confronting negative interpersonal peer influences from tobacco to drug use, but often fail to do so when experiencing sexual pressure regardless of their health status. HIV positive youth, however, are under additional pressure to be assertive in interpersonal sexual negotiation matters to avoid further spread of HIV transmission. As a remedy, assertiveness training is recommended for HIV positive youth. With assertiveness training, HIV positive youth will also have the skills to facilitate their health care by forming patient-healthcare teams (Whitworth, 2007).

A recent study conducted by Dr. C.A. Beasley-Smith et al compared “at risk” homeless adolescents to adolescents deemed at no risk. Predictably, their research indicated that homeless youth were more likely to show poorer assertiveness skills (Beasley-Smith, 2008). Trends in the research findings indicate that HIV positive youth have low assertive levels as well. This research is far from conclusive as limited studies have been conducted on HIV positive youth’s

assertiveness, and more research is needed in this area.

PATIENT ADVOCACY

The use of patient advocates in chronic healthcare is common place (Roizen, 2006). Considering the complexity of HIV infection using patient advocates to represent the needs of homeless youth is prudent (Grodeck, 2003). One of the major challenges to using patient advocates for HIV positive youth is finding enough advocates that can meet the high number of youth (Lee, 2007). The alternative to using patient advocates is to teach youth to advocate for themselves. Teaching youth to advocate for themselves will prepare them for living with HIV (Small, 2006). Researcher Sale showed that quality relationships between adult service providers and youth empowers youth and strengthens health outcomes.(Sale, 2008)

FUTURE PLANNING AND GOAL SETTING

While for some it may seem counterintuitive for perinatally born HIV positive youth who by late adolescence are long-term survivors to plan for an adult life, many perinatally born adolescents may live well into their 30s or longer. Even if a perinatally infected youth’s long-term prognosis predicts an abbreviated life, there are still compelling reasons to engage perinatally youth in long-term future planning and short-term goal setting. Conversely, behaviorally infected adolescents have the greatest potential for a longer life

span of all other HIV positive age groups (CDC, 2004), making future planning for these youth also crucial.

The majority of treatment programs for HIV positive youth offer life skills training, including future planning and goal setting. Project Orion incorporates life skills training in their case management programs for HIV positive youth. Planning is implemented to assist with medication adherence programs designed for HIV positive youth on antiretroviral treatments (The UCSD Mother Child & Adolescent HIV Program, 2008). Training HIV positive youth to plan ahead has been indicated as a tool to maintaining their long-term health and adherence to medication therapies.

KEEPING A FILE OF IMPORTANT INFORMATION

Starting a file of important documents can be a daunting task for HIV positive youth. Although teaching HIV positive youth to become responsible for their formal documents and medical information is important, little information is available on this topic. The majority of programs designed for HIV positive youth cite training youth in health document maintenance and storage as a best practice. Still, views differ on the best methods for the age appropriateness of when to begin this training and have this expectation of youth clients. The varying ages and capacities of HIV positive youth, who by some definitions vary

from age 13 to 29, for maintaining such crucial information is a key consideration.

One method that some programs utilize is the Shah method. A public health researcher and practitioner, Dr. Jay P. Shah believes that maintaining important documents in a single binder that can be found in a central location is the easiest way for youth with chronic health conditions to meet these responsibilities. Shah's method may also be a tool for addressing the privacy protection concerns in addition to the document maintenance issues for HIV positive youths (Shah, 2006).

NAVIGATING FEDERAL SUPPORT SYSTEMS

Applying for and receiving support from federal systems can prove challenging for HIV positive youth, especially for those who are homeless. It is an ongoing challenge for programs to reach homeless HIV positive youth so that early case identification and complex treatment regimens can be initiated and tailored to meet their individual needs. Nonetheless, it is a necessary challenge to tackle in order to positively affect their long-term health outcomes (Woods, 2003). Programs offering services to HIV positive youth that also assist them in navigating federal support systems tend to retain clients in long-term care programs (English, 2003). Most multi-service outreach programs for HIV positive youth provide assistance in applying for and navigating federal support systems (Children's

Hospital Boston, 2008). Programs offering assistance in navigating federal support systems are able to retain more HIV positive youth than those that do not (CDC, 2008).

EDUCATION

In 2004, data from the U.S. Department of Education concluded that while 87% of homeless youth are enrolled in school, only 77% attend school regularly (U. S. Department of Education, 2004). A report by the National Coalition for the Homeless (NCH) cites school as one of the few stable, secure places in the lives of homeless HIV positive youth –a place where they can acquire the skills needed to help them escape poverty (NCH 2008). A recent study, suggests that meaningful change in the lives of homeless HIV positive youth should utilize interventions that go beyond the individual and instead be geared toward modifying the social context of individuals' lives (Bantchevska, 2008).

Peer support and influences can come through youth social networks but it can also come through the educational setting. Survey research conducted by Dr. Eric Rice concluded that interventions should target newly homeless HIV positive youth in networks that contain problematic peers and strive to harness the naturally occurring pro-social peer influences present in these networks (Rice, 2007). Rice also found that having peers that attend school was listed in the Rice study as having a positive pro-social effect on homeless

HIV positive youth. Providing a mechanism to educate homeless HIV positive youth has been linked to retaining them in programs designed to address their needs (YouthCare, 2008). All of the research findings regarding educating homeless youth conclude that involving homeless HIV positive youth in school can improve youth's overall health and psychosocial outcomes. Clearly, programs seeking to maintain HIV positive youth in care should identify best practices or develop strategies that can assist them in maintaining youth in some form of educational setting, particularly as a stabilizing force in the often chaotic lives of homeless HIV positive youth.

HIV INFORMATION IN SCHOOLS

A summary review we conducted of HIV prevention curriculums implemented in the public schools of major urban school districts located in high HIV prevalence areas across the nation (Cleveland, Atlanta, Houston, Chicago, Baltimore, Philadelphia, New York City, and Washington, DC, etc.) found that almost all school-based HIV prevention curriculums approached youth in school as though the targeted youth were already HIV negative. Though this is appropriate for the majority of the target populations these systems seek to reach, it means that those already HIV infected receive little school-based HIV prevention information and education. Further, researchers should investigate whether presenting school-based HIV prevention information and education with the base assumption that the

exposed audience is uninfected or affected by HIV contributes to the stigmatization of HIV positive youth as victims of a rare and unusual occurrence among youth. Additionally, given the paucity of research on school-based referrals and secondary prevention information for HIV positive youth, there may need to be additional local and national assessments done on the availability of school-based health resources for HIV positive youth. Needs assessments should also determine an educational systems' knowledge and capacity to provide a supported referral by school nurses, counselors, or other school-appointed health officials to care and support services in their students' local community.

Primary HIV prevention education in schools is still the primary method health departments and school boards across the country use to provide HIV prevention information for general population youth. While the success of these education and intervention programs vary, it is clearly a core component in preventing further spread of HIV among youth and can at least provide HIV positive youth with general information that can mitigate further spread of HIV to those uninfected.

The method for delivering information in the schools is in contention, particularly when it comes to peer education programs in schools, with data supporting both sides of the argument. A 2005 study of HIV/AIDS education implementation in Massachusetts public

schools concluded that strong, state-level HIV prevention education policy recommendations can help shape local school health policy and can positively influence the reach and quality of HIV education (Blake, 2005). Dr. Angela Ebero, however, suggested that the practice of using peer educators in school-based HIV education may have a negative effect on the peer educators that has not been evaluated (Ebero, 2002).

Dr. Linda Gilliland's view is the opposite of Ebero's. The study conducted by Gilliland showed that programs using peer educators and HIV positive youth-initiated websites can increase peer educator's knowledge and self-esteem and help reduce risky sexual behaviors. Gilliland's study also concluded that because many school-based health centers (SBHC) provide services beyond traditional primary care, there is great need to support and increase the number of SBHC prevention programs targeted at communities at risk (Gilliland, 2005).

The most innovative study for youth-specific HIV prevention we identified was conducted in Tanzania. The research program serviced only males and used sports to promote HIV/AIDS education for at-risk youth. Results of the Tanzania study showed increases in knowledge and retention of information on HIV/AIDS prevention (Maro, 2008).

With the exception of Ebreo's study, all other studied school-based programs we reviewed used some form of peer educators. Ebreo's research does raise some concerns. Research to support or negate Ebero's has not been completed at the time of this publication. Reaching youth in school programs has been linked to reducing stigma for HIV positive youth.

HOUSING

The housing needs of HIV positive youth vary greatly. Some youth are able to live with their families, while others are kicked out after disclosing their newly diagnosed HIV status to their families (The Media Project, 2008). Shelters for homeless HIV positive youths often turn them away youth if they are under 21 (Montero, 2008). Far too many shelters are short-term emergency housing programs offering extremely limited stays with even more limited programmatic opportunities. Programs offering housing to HIV positive youth should also incorporate services that address their additional psychosocial and medical needs (Crossroads Programs Inc., 2008). Offering only temporary housing makes it difficult to employ the messaging and programmatic reinforcement youth need to support overall holistic health and treatment maintenance. Longer-term housing programs like transitional living programs for homeless HIV positive youth offer an active alternative to shelters for youth and can be designed to meet the needs of different sub-groups within the

homeless youth population (Jarvis, 2003). However, limited funding support for longer-term transitional living programs exclusively serving HIV positive youth make these programs rare, particularly outside of urban centers.

SOCIAL SKILLS

Research conducted at Boys and Girls Town has determined that there are eight basic social skills that all youth need to be successful in communications and interactions across their lifespan. The basic social skills are: following instructions, disagreeing appropriately, accepting criticism/consequences, talking with others, showing respect, accepting 'no' for an answer, introducing yourself and showing sensitivity to others. For HIV positive youth acquiring social skills, it is important to their needs to communicate with their health care and social service providers effectively. Telephone skills such as: tone of voice and manner when speaking and not letting the frustration of waiting result in rude or explicative language are additional social skills that HIV positive youth must master. Although primary care physicians need appropriate communication skills and knowledge of HIV positive youth health issues, HIV positive youth are ultimately responsible for communicating their own health care needs. Issues such as the need for confidential services and networking with social services will have to be communicated by HIV positive youth to their

physicians and case management teams (Meynard, 2008).

HIV positive homeless youth, because of their marginalized status, will need programs designed to develop or help re-educate them on social skills potentially lost as a result of living on the streets. Increasing and reinforcing the social skills of HIV positive youth may be a tool for longitudinal antiretroviral adherence among adolescents infected with HIV (Murphy, 2005). Numerous articles have been written on the importance of adults communicating with their health care team members. Yet, there is little information on the subject of HIV positive youth communicating with health care team members, because of the dependent status of some HIV positive youth. Youth transitioning into adult care will be required to assume many of these mature and occasionally assertive social skills to receive proper care.

Primary care physicians also need appropriate communication skills and knowledge of specific adolescent health issues. To help youth stay in care, physicians also need an understanding of the unique issues facing HIV positive youth, such as an even more emphasized need for confidential services (than those assumed for general health practice), networking with social services (to create wrap around services for youth) and the role of other key supports in the lives of HIV positive youth (Meynard, 2008).

DOMESTIC VIOLENCE

HIV positive youth that disclose their status to partners are often attacked (Grodeck, 2003).

Dr. Susan J. Klein conducted research that indicates interventions are needed to prevent intimate partner violence (IPV) against HIV positive youth (Klein, 2008). Dr. Danielle C. Payne's work focuses on Ohio's domestic violence profile. Payne identifies resources for victims and challenges faced by GLBT and HIV positive youth (Payne, 2007). The articles and research reviewed conclude that limiting domestic violence in the dating relationships of HIV positive youth involves educating them to avoid abusive partners and increasing self-esteem.

MENTAL HEALTH

Numerous studies have been conducted and indicate that mental health support must be included in all long-term care plans for individuals in the HIV positive community. Considering that adolescence and young adulthood is the time period in which many psychiatric disorders manifest, little has been done to describe and quantify what mental-health problems HIV-positive children and adolescents uniquely or disproportionately face (Scharko, 2006). One study conducted in South Africa discovered that a majority of teens experience depression after testing positive for HIV infection (Earls, 2008). While depression is the most frequent mental health challenge experienced by HIV positive youth, many other mental health issues do occur (Benton, 2008).

Post-traumatic stress disorder can occur in teenage youth following receipt of an HIV diagnosis (Gaughan, 2004). The research findings inform professionals about the potential impact of HIV diagnosis on adolescents and young adults, particularly as this may impact participation in medical care and need for mental health support.

Clinical reports from the United States indicate substantive mental health problems in perinatally human immunodeficiency virus (HIV)-infected youth that pose substantial barriers to optimizing their health. A pilot study exploring the rates and types of psychiatric and substance use disorders, as well as emotional and behavioral functioning in perinatally HIV-infected children and adolescents found the following using standardized assessments of youth psychiatric disorders and emotional and behavioral functioning, as well as measures of health and caregiver mental health:

According to either the caregiver or child report, of forty-seven perinatally-infected youths 9-16 years of age, 55% of youths met criteria for a psychiatric disorder. The most prevalent diagnoses were anxiety disorders (40%), attention deficit hyperactivity disorders (21%), conduct disorders (13%), and oppositional defiant disorders (11%) (Mellins, 2006).

This study concluded that standardized assessments of mental health identified very high rates of psychiatric disorders, primarily in the anxiety and behavioral domains, in this

sample of youth with perinatal HIV infection. Mental health interventions should be integrated into medical care to help members of this highly vulnerable population to optimize their health and well-being.

While we failed in our review to find research on any potential challenges related to youth disclosure of their HIV status to mental health practitioners, participants raised concerns regarding youth potentially failing to disclose their HIV status to prescribing mental health professionals during key informant interviews. Interviewed youth social service providers were concerned that not only might youth not be disclosing their HIV status to their mental health providers writing prescriptions to antidepressants, anti-psychotics and other psychotherapeutic drugs, but that those providers may not be surveying youth clients at intake for their HIV status. This neglect by both clients and practitioners, driven by clients' failure to disclose based on stigma, may lead to mental providers prescribing medicinal therapies that could dangerously interact with clients' antiretroviral medication. Depending on the therapies, such interactions could mean an unintended reduction or increase in the dosage of certain antiretroviral medications, impacting their effectiveness. To determine whether this is indeed an under-researched trend or anecdotal incidents, additional research needs to be conducted. In the interim, youth clients should be encouraged to disclose their HIV status to mental health providers and ask

pharmacists about potential drug interactions for medications differently prescribed by a client's mental health and primary care physicians as part of a client's care maintenance.

UNDERSTANDING RELATIONSHIPS

AIDS is a disease, just like cancer or any other disease — *it's not a curse from God* (Lynn, 2001). Behaviorally infected HIV positive youth often feel guilt and shame for life choices that led to their HIV positive status (LoConte, 2008). During any chronic illness, support of friends and family members is critical to long term health outcomes. For youth living with HIV, relationships are significantly more important. Many young people who contracted HIV through perinatal transmission are facing decisions about becoming sexually active (CDC, 2007) and some are struggling with desires to become parents and start a family as an immediate goal. Expectations most young people have for a life including sex, intimacy, loving relationships, and family are no less apparent in HIV positive youth. The realities of living with HIV can sometimes bristle against these expectations causing emotional distress.

Although limited information is available on the suicidal ideations in HIV positive youth, numerous studies have been conducted on depression within HIV positive youth populations (Quintana-Ortiz, 2008). A great deal of depression is due to the changes to interpersonal relationships that occur after

diagnosis of HIV infection (PositiveLife.net, 2005). Fear of disclosure and stigmatization contribute to bad outcomes. In 2001, CDC found that 1 in 5 people stigmatize HIV (CDC, 2001). Equipping HIV positive youth with a complete understanding of HIV will be a tool to combat stigmas and improve interpersonal relationships.

LEISURE SKILLS

The majority of HIV positive youth has experienced depression or will at some point in the future (Cobain, 2007). Prior to becoming HIV positive, behaviorally infected youth were engaged in activities that were considered high risk (Wisniewski, 2005). Leisure skills and learning how to have fun safely are important skills for HIV positive youth to learn. Physical and leisure activities improve the emotional and physical well-being of HIV-positive youth (Ramirez-Marrero, 2004). Aerobic exercise training may help prevent or reduce depressive symptoms experienced by youths living with HIV infection (Neidig, 2003). Leisure skills and physical activity may mediate the effect that stigma, fatigue, loneliness, decreased social support, neurological changes, declining health, changes in appearance, and financial distress have by improving overall health for HIV positive youth (Strohle, 2008). The impact of leisure skills and physical activity may be a critical and innovative tool for treating depression in HIV positive youth.

DECISION-MAKING SKILLS

That HIV positive youth engage in high risk behaviors is widely known. Programs designed to meet the needs of HIV positive youth that have incorporated decision making skills into their programs have been more successful in maintaining HIV positive youth in treatment (CDC, 2004). These more comprehensive programs also lead to reduced risk behaviors among HIV positive youth. Introducing decision-making skills to behavioral treatments of HIV positive youth have led to longer life span, improved quality of life, and fewer psychiatric problems (Donenberg, 2005). Investigators searching for differences between HIV positive youth and individuals of other ages to explain the relatively more frequent risky behavior of HIV positive youth have come up empty handed (Donenberg, 2005). Palmer believes it is necessary to teach HIV positive youth refusal skills and positive attitudes to meet the challenges of life in a world which requires them to grow up before their time (Palmer, 2000).

MONEY MANAGEMENT

Like most Americans, HIV positive youth rarely receive instruction on money management. For HIV positive homeless youth, lack of money management skills impedes their transition to independent living (National Youth Advocacy Coalition, 2008). During the 2008 12th Annual U.S. Conference on AIDS, money management was cited as a core stabilization tool for the chronically ill and marginally housed.

Transitional housing programs that assist HIV positive homeless youth with living skills have not traditionally incorporated money management skills into their programs (Crossroads Programs Inc., 2008). As the number of homeless HIV positive youth increases, teaching money management may help them maintain or transition easier to housing. Currently, there are no nationally known programs that incorporate money management skills with programs designed specifically for homeless HIV positive youth.

CREDIT

The United States is a credit based society. Everything from apartments to jobs are credit based. However, no information exists on credit and HIV positive youth, despite HIV positive youth potential to disproportionately face credit woes. HIV positive youth ages 18 to 21, like many other college-age youth, may be preyed upon by credit card companies and have little understanding of how credit works or how it can effect—even in the short-term—their ability to obtain jobs, housing, private student loans and other core young adult needs. Depending on the youth's view of their long-term prognosis and life longevity, they may see little need in educating themselves on credit and view credit card offers as “free money” opportunities to treat unscrupulously. Clearly, an education on the short- and long-term ramifications of establishing poor credit regardless of HIV status is necessary.

Not being able to establish credit can be as detrimental as establishing poor credit. It is difficult to obtain credit cards and financing without a stable home address. HIV positive youth that are homeless, in addition to dealing with ageism and potential discrimination from landlords, will also have to face credit challenges to find permanent housing without a credit history.

For practitioners seeking to educate young clients on credit, both Kathering Deering and Len Gautier offer useful resource tools deciphering the language used in credit files in layman's terms easily accessible for youth (Deering, 2005; Gautier 2006). Deering's book provides a complete overview of personal finances and Gautier's on credit. Both books include helpful practical information, such as how to keep track of personal finances and how to create a personal budget; and what to look for in school or automobile loans.

TRANSPORTATION

All programs that provide services to HIV positive youth also offer transportation assistance. Programs located in major cities offer tokens or transportation vouchers (Children's Hospital of Philadelphia Adolescent HIV Initiative, 2008). Programs in rural areas often can not offer transportation services to HIV positive youth. One method to address the needs of HIV positive youth used in Florida has been carpooling and offering pick-ups to HIV positive youths. Programs located in areas

with public transportation systems offer bus tokens or metro fare cards (up to and including monthly transportation cards) for clients to get to *and* from appointments to support program retention.

HEALTH

Obviously, general health maintenance is the major concern in treating HIV positive youth (Healthy Teen Network, 2006). Mental health, physical fitness, alcohol and substance abuse and sexually transmitted infections are all factors impacting the health status of HIV positive youth and may require other treatments combined with their HIV positive treatment (Romano-Spica, 2008).

Nutritional status has also been linked to improving long-term health in the HIV positive youth (Fields-Gardner, 2003). Research by Dr. Henrik Friis has revealed that micronutrient balance is as important as traditional nutrition in maintaining optimal health among HIV positive youth (Friis, 2002). The cited studies agree that maintaining optimal nutritional balance is important to the quality of life for HIV positive youth. Alcohol and substance abuse among HIV positive youth has been linked to depression. Studies cite that treating depression prevents the self-medicating behaviors (i.e., alcohol, substance use, etc.) of HIV positive youth. Although, the CDC has recommended that mental health services be included in treatment regimens for HIV positive youth, many HIV positive youth do not

have access to mental health services geared to their needs (Lyon, 2006).

STIs AND HIV

Current prevention programs focus on preventing HIV and other sexually transmitted infections (STIs) in non-infected youth.

However, the HIV positive population also needs to be educated on the effects that STIs, including HIV, will have on their personal freedom and current treatments. Two STIs of particular concern for HIV positive youth are Genital Herpes (HSV-2) and superinfection of HIV. HIV positive youth that unknowingly have a partner with HSV-2 may transmit HIV to their partner (Abu-Raddad, 2008). Although, both partners are responsible for non-disclosure, current trends globally indicate that the HIV positive youth may face prosecution.

“Super infection” of HIV is a hotly debated topic in the medical community. Superinfection is defined as the re-infection of an individual who already has an established infection with a heterologous HIV strain. Controversy surrounding superinfection exists because it has implications concerning our understanding of worldwide HIV diversity, individual immunity and disease progression, and vaccine development (Smith, 2005). As anti-retroviral therapy becomes increasingly available, young people living with HIV need tailored support to adopt safe sexual behaviors. Currently, there is a gap in secondary prevention and sexual risk reduction targeted to HIV positive youth

(Bakeera-Kitaka, 2008) when compared to the proliferation of primary HIV prevention programs across the U.S. However, with an increased domestic focus of CDC resources on identifying and engaging HIV positive individuals on HIV risk reduction instead of broadly focusing their energies on at-risk individuals, there has been a fundamental paradigm shift in public health on how HIV prevention will be addressed in the years to come.

Educating HIV positive youth about the consequences of not practicing safer sex, including heightened risk for STI co-infection or re-infection with a potential drug-resistant HIV strain all factors into positive long-term healthcare outcomes. Youth also need to be educated about the potential legal consequences of not engaging in risk reduction measures and of not disclosing their HIV status (in several states, including Ohio, it is a felony offense for infected individuals to engage in sexual activity with others without disclosing in a method that can be proven in a court of law). In the enclosed appendices, provider guidance on conducting secondary HIV prevention and support for treatment adherence are outlined as a reference for providers.

SOCIAL SUPPORT

Mechanisms to provide social support to HIV positive youth have been implemented in a variety of programs serving them. Social support including events, structured activities,

group discussions, and artistic expression have been successful in improving overall quality of life for HIV positive youth (O'Brien, 2008). Other programs offer social support by providing a family-centered approach to care for HIV positive youth (The University of Florida Rainbow Center, 2008). Another social support mechanism for HIV positive youth has been offering job training skills and workforce development training to prepare them for self-sufficient independence (YouthCare, 2008). In addressing the needs of HIV positive youth, the idea of providing social support for the “whole” person is critical to their overall well being (Benton, 2008).

FAMILY RESPONSIBILITIES

Homeless HIV positive youth are on the streets for a variety of reasons. Some HIV positive youth leave home to avoid dangerous situations while others either leave or get kicked out due to disclosure of their GLBT orientation (Cochran, 2002). A common factor for homeless HIV positive youth is unresolved issues regarding their parents which can contribute to their high risk behaviors (Engel, 2005). Dr. Susan Forward claims that homeless HIV positive youth are often victims of parental or guardian abuse and need help dealing with their abusive past (Forward, 2002). Another common theme in the research involving homeless HIV infected youth is that breaches of trust in relationships with parents have been translated to psychological pain, un-reconciled traumas that can provide the foundation for

“acting out” behaviorally in ways that prevent healthy living and positive decision-making. Providing the mental health resources to help homeless HIV positive youth address unresolved issues may be essential to decreasing the levels of depression that can occur in homeless HIV positive youth.

PREGNANCY AND ANTIRETROVIRAL MEDICATIONS

Approximately 5-10% of all cases of HIV are children (those under age 12). Most research on HIV positive children focuses on preventing perinatal transmission of HIV infection. The majority of children acquire infection through mother-to-child transmission either during pregnancy, delivery, or by breast-feeding (Saharan, 2008). One study believes that routine rapid testing during labor provides a feasible, acceptable, and accurate way to identify HIV-infected women before delivery (Rahangdale, 2008). In a recent study, Dr. Jeffery J. Weiss raised the questions of the safety of agents used to prevent mother-to-child transmission of HIV (Weiss, 2008).

Many have argued that comprehensive sexuality education inclusive of pregnancy prevention education for youth needs to be available to ensure that young HIV positive women reduce their likelihood of experiencing an unintended pregnancy. Some HIV advocates argue for states to mandate HIV testing as a routine part of prenatal care (which many states require) to identify the potential for

perinatal HIV transmission and provide pregnant women the option of preventative HIV treatment for their unborn child. Many HIV positive women discover their HIV status for the first time during screenings conducting as a routine part of prenatal care. Clearly, a lack of access to comprehensive sexuality education and accurate pregnancy prevention information, minimal youth access of HIV testing services, and poor youth access to prenatal care each play a role in the continuation of perinatal HIV infections across the country.

Too often current research on HIV and pregnancy fails to investigate how access to care and treatment affect women's childbearing intentions (Gruskin, 2008). A clear research agenda is needed to create a more coordinated approach to policies and programs supporting the pregnancy intentions of women with HIV (Fowler, 2007). Pregnancy and HIV risk reduction interventions targeting young seropositive females are also needed (Koenig, 2007).

There is limited guidance for social service practitioners faced with youth clients who desire pregnancy. Practitioners should refer their clients to a medical specialist for specific guidance on clinical methods such as “sperm-washing” for HIV positive men and anti-retroviral therapy and C-section delivery options for pregnant HIV positive women. Further, both provider and pregnancy-seeking

client(s) should familiarize themselves with CDC guidance and fact sheets (available through the CDC website) on HIV positive pregnancies. While pregnancy is not necessarily recommended for young HIV positive individuals, particularly those lacking resources and supports, there are medical strategies available for HIV positive clients seeking guidance on how to achieve a “safer” pregnancy that is less likely to result in perinatal HIV transmission.

BASIC UNDERSTANDING OF THE LAW AND HIV

In his book, Judge Tom Jacobs gives teen readers a behind-the-bench look at the juvenile justice system and the young people whose lives are often changed in court (Jacobs, 2003). Jacob's book provides a framework for understanding how the juvenile justice system affects youth and its importance in addressing and in some instances exacerbating the issues of HIV positive youth offenders. Proper care, support and treatment of HIV positive youth offenders is more challenging to meet within an incarcerated setting with the appropriate skill and sensitivity accessible within the social service network outside of these settings. As difficult as it may be to identify effective HIV positive youth programming in a public setting, many privately owned juvenile rehabilitation facilities may prove even more challenging for social service vendors to access (particularly without pressure from their public funders)

and for youth to navigate and receive proper care and support.

HIV positive youth need to also be aware of the new legal implications and responsibilities their health status poses in many jurisdictions and, indeed, around the world. A study conducted by Azad reviews the global trends toward prosecuting for the transmission *or even the potential transmission* [emphasis mine] of HIV infection to non-infected individuals (Azad, 2008). The conviction of a HIV positive man in Dallas for spitting on a police officer emphasizes trends towards criminalization of HIV that HIV positive youth should be aware of. As previously mentioned, HIV positive youth may also be prosecuted from a misdemeanor up to a felony offense, depending on the state, for a failure to disclose their HIV status to their intimate partners using methods qualifying as evidentiary in a court of law. Providing HIV positive youth with thorough legal information related to the legal status of their disease and their potential experience within the correctional system as an HIV positive individual can prevent them from becoming unknowing offenders and may prove coercive in reducing their likelihood for becoming an intentional one.

There are also worker rights and legal employment guidelines germane to HIV positive individuals, that youth should be able to readily access in the event of a legal matter. In the appendices of this manual there are

outlines of the legal guidelines regarding HIV positive workplace rights and protections for a provider's reference when educating and working with youth on legal and employment concerns.

MENTORING AND PEER COACHING

Mentoring relationships are associated with positive adjustment during the transition to adulthood for HIV positive youth (NYAC, 2008). Studies show that peer mentoring can have a positive effect on HIV positive youth. The best example of the positive effect of peer mentoring on HIV positive youth can be found at the Bay Positives program. Established in 1990 as the first peer-run agency in the world for young people living with HIV/AIDS, Bay Area Young Positives helps HIV positive youth live longer, healthier, happier, and productive lives (Bay Positives, 2008).

Some programs use long-term survivors to mentor newly diagnosed adolescents and young adults. These often cross-generational mentorship programs should be closely monitored by clinicians or practitioners with a mental health background. Cross-generational mentors should also be thoroughly trained in adolescent development, boundary setting, boundary maintenance, partner roles and responsibilities within a relationship with an uneven power dynamic, and the potential psycho-social challenges uniquely facing a newly diagnosed young person without mature cognitive capacities. Organizations considering

mentoring partnerships between HIV positive youth under the legal adult age with legally adult long-term survivors should also investigate their legal exposure to suit, the insurance implications of such a program, have written participant codes of conduct policies and violation remedy procedures that are universally understood—and signed off on—by all parties, and the institution of police or Federal Bureau of Investigation (FBI) background checks on adult mentors to assist in protecting the youth from predatory harm and the organization from possible legal culpability in the event of any physical or psychological harm to either party. Traditional intergenerational mentorship programs offer a variety of proven tools, best practices and scientifically validated models of programmatic service that can be identified through Community Action Associations, The National Mentor Center, and the US Department of Juvenile Justice, Office of Justice Programs.

PROGRAMS FOR HIV POSITIVE YOUTH

Most major U.S. cities have at least one program to meet the needs of HIV positive youth. All of the programs that work with HIV positive youth provide some form of medical assistance to youth clients. There are four models of how services are delivered to HIV positive youth:

- A meta-program offering services to homeless youth that also hosts a micro-program designed to meet the

additional needs of HIV positive youth. (Examples include: the Larkin Street Youth Center, the Orion project, and Crossroads Program's, Project Discovery);

- A HIV positive youth program within a medical center, designed almost exclusively to meet the physical and mental health needs of youth (but not housing, etc.) (Examples include: Project ARK, Youth Angle, Horizons Project, Boston HAPPENS Program, Adolescent Initiative Program of the Children's Hospital of Philadelphia, and Special Programs for HIV/AIDS at the University of Miami);
- A HIV positive youth program within a community based facility offering a range of services and referrals to only HIV positive youth or both at-risk HIV negative and HIV positive youth. (Examples include: Metro Teens in Washington, DC and Bay Area Young Positives in San Francisco);
- And, a HIV positive youth program within a family program that offers comprehensive family-centered care. (Examples include: the University of Florida Rainbow Center at Shands Jacksonville, and the UCSD Mother Child & Adolescent HIV Program).

Each model provides HIV positive youth with access to services necessary for treatment of the bio-medical components of HIV infection.

However, based on research findings, more programs need to focus on addressing the psychosocial needs of HIV positive youth.

CONCLUSION

Numerous articles and research information is available on the bio-medical impact of HIV infection in adults. Research on how HIV affects development across the lifespan of HIV positive youth is limited. Studies of HIV positive youth's responses to depression, a key indicator of suicidal ideations, are almost non-existent. The majority of research published regarding HIV focuses on progression and treatment in adults. As the number of youth living with HIV increases it is becoming more important to research the unique experiences and challenges that youth face to provide services that meet their needs.

Best Practices in Youth Care, Service, and Transition

INTRODUCTION

What does it mean to transition an HIV positive youth to adult care? According to the Human Resources and Services Administration (DHHS, 2007), transitioning is “the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from a child/adolescent-centered to adult-oriented health care systems.” Transition has also been defined as a process rather than a point in time, one where transfers to new or different services, personnel or place of care occurs (Family Clinic, 2007). How transition happens depends on individual agencies and the resources and services available to them. Transition from pediatric or adolescent health services to adult care has been standard for youth with other chronic health conditions such as diabetes and may provide organizations with more studied guidance and proven best practices for replication, particularly for those organizations operating under a medical-model. In the HIV/AIDS field, no standard model of care exists for transitioning adolescents to adult care (DHHS, 2007).

The lack of a standard model of care comes at a time when more young people are becoming HIV positive. Half of all new HIV infections in the United States occur among people under age 25. HIV positive youth are surviving their HIV diagnosis years longer than youth were in the early years of the epidemic. Even older children with vertically acquired HIV infection are experiencing a longer lifespan, since the introduction of HAART. Increasingly, these youth are turning to Ryan White funded programming for services. In 2005, there were nearly 12,000 HIV positive Title IV clients between ages 13 and 24 years old. While infected youth are living longer with HIV, they are also presenting to services with a myriad of complex psychological, cognitive and social concerns. Therefore, services seeking to transition young adults into adult care must contend with issues beyond primary medical care.

WHAT ARE THE GOALS OF TRANSITIONING YOUTH TO ADULT CARE?

The goal is to successfully transition youth to adult care in such a seamless and effective manner that client access to continuum of care services goes uninterrupted, treatment adherence is maintained, and client retention in care is sustained. According to a HRSA report on transitioning HIV positive youth to adult care (DHHS, 2007), the skills and responsibilities youth should ideally acquire through transitioning include:

- 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
- Acknowledging and negotiating obstacles to care

Dr. Jeffery M. Birnbaum of SUNY Downstate Medical Center offers a more exhaustive listing of life skills transitioning youth should be able to effectively complete by the end of a transitioning process (Birnbaum, 2008). According to Dr. Birnbaum, the life skills preparation needed for adolescents to successfully transition into adult care are:

- Knowing when to seek medical care for symptoms or emergencies
- Being able to identify one's symptoms and describe them
- Using one's primary care provider appropriately
- Making, canceling, and rescheduling appointments
- Coming to appointments on time
- Calling ahead of time for urgent visits
- Requesting prescription refills correctly and allowing enough time

for them to be refilled before needed

- Negotiating multiple providers and subspecialty visits
- Understanding the importance of healthcare insurance and how to get it
- Understanding entitlements and knowing where to go for each
- Establishing a solid relationship with a new case manager

While Dr. Birnbaum's list is thorough, there are key elements related to general youth health, developmental and human service needs that are also important in transitioning youth not only into adult care, but into adulthood. It is crucial that both the youth and the adult provider agencies transitioning legally adult but cognitively immature young people are getting these needs attended to before transitioning or in the early stages of transitioning clients into adult-oriented medical services.

WHO ARE "TRANSITIONING" YOUTH?

Age

Every hour, two Americans aged 13 to 24 are infected with HIV; these are the young people generally described when discussing HIV positive adolescents and young adults in the US. Adolescent health clinics and programs working with HIV positive youth may work with young people up to age 27 years old. Youth are transitioned into adult care when

they are as young as 18 to as old as 27 years of age, depending on the program and agencies “age-out” policies. The average age range for youth transition usually occurs between ages 19 to 21 years old. Programs use age as one of several markers to help define the expected developmental capacities of youth clients for practitioners transitioning youth. Providers using this guidance try to progressively provide new information, train young consumers on new skills, and increase both knowledge and responsibilities for youth consumers according to projected, developmental capacities anticipated at each age stage. Models for graduating, age-based knowledge and skills improvement as key components of transitioning youth will be outlined later in this chapter. It is important to note that age is but one of several characteristics considered when determining the best approach for transitioning youth into adult care.

Racial and Socio-Economic Characteristics

Whether HIV was vertically or behaviorally acquired, both CDC surveillance data (CDC, 2007) and HRSA client statistics (DHHS, 2007) indicate that the majority of HIV positive youth in this country are:

- members of a racial and ethnic minority;
- economically challenged;
- and/or lack private health insurance and medical resources.

Emerging populations among newly infected youth include:

- African American and Latino young men who have sex with men
- African American young women
- Latina young women
- Young transgender women of color
- New immigrant youth populations from Africa, Caribbean and Latin America

Each of these populations may bring different needs, expectations and require baseline understanding by practitioners of the potential cultural experience or world view of their clients to assist providers in partnering with clients to identify and address their specific issues and concerns.

Cultural Competency Needs

Less than a third of programs we surveyed explicitly addressed issues of race, gender expression or sexual orientation in their service delivery or identified it as a critical program component for success. Yet, cultural competency training was repeatedly acknowledged as an important aspect of their staff members overall programmatic training. Research suggests successful agencies ensure program staff receive on-going cultural competency training, apply trainings in their program design, and use their cultural competency education to administer relevant and appropriate service delivery with clients.

Cultural competency may be particularly important when working with youth from immigrant families who may have a different value system around issues such as disclosure, independence, and assertiveness (Lyall, 2003; Melvin, 2008). Lesbian, gay, bisexual and transgender (LGBT) youth may also disproportionately experience isolation, depression, substance use and housing issues socially related to their sexual orientation, gender expression or HIV status. It is therefore important that providers, in an effort to ensure equal treatment and fairness regardless of their clients' social identity, not assume all HIV positive youth are culturally the same. In the absence of training and monitoring in this area, youth clients may be addressed according to the cultural assumptions or value systems of practitioners, rather than in deference to the client's real-life context.

Of course, cultural competence trainings are but one key element to ensuring quality care to—and retention of—youth clients. In complement to cultural competency education, client centered counseling has also been proposed as a remedy to provider-centered counseling, where the goals, concerns, and perspective of the provider are privileged over those of the client. Client-centered counseling as the best practice promoted by surveyed providers cannot be overstated. If an organization is client-centered in their service delivery and practices, they will achieve better client health and retention outcomes in case

management and in treatment adherence. Few strategies have proven as successful as listening to consumers and asking open-ended questions about the cultural context and concerns governing their lives, informing their morals and values, and helping to define their relationship with themselves, society and the institutional systems they will need to navigate to achieve a successful transition. When client-centered approaches are implemented as an aspect of clinical care, with youth as informed partners in clinical decision making, providers can better identify the potential for client success in treatment adherence and are more likely to receive critical information about client's experience with disease progression and prescribed treatment regimens.

Economic Issues and Identity

According to the Kaiser Family Foundation, to be an adolescent is to inherently be poor or economically challenged (Kaiser, 2003).

Financial resources and support for children's well-being usually come through parents, families, or government systems. In the absence of these support systems, youth often lack the resources to adequately maintain their health, well-being and core human service needs (i.e., food, shelter, transportation).

Many youth can obtain work in an effort to afford independent living. However, youth employment in the United States is difficult to steadily maintain, even when youth possess the skills, maturity, and capacities to retain stable

employment. Youth employment is also primarily offered in part-time and temporary positions in minimum and low-wage jobs in sectors (i.e., retail, service, telemarketing, etc.) uniquely vulnerable to economic shifts, such as recessions and changing attitudes in consumer spending. These insecure economic realities provide for further uncertainty for youth transitioning not only into adult care, but also adulthood.

HIV positive youth aging out of adolescent services may also simultaneously be aging out of foster care or expected to move out of their family's home into their own dwelling upon reaching legal maturity, without having yet the earning potential to achieve complete self-sufficiency. Youth whose housing and other basic human service needs have been met by primary care givers, foster care or other governmental systems—depending on a jurisdiction's available resources—may experience compounding anxieties about these multiple transitions and their own limited abilities to fully meet all these developmental expectations and economic obligations simultaneously. The cumulative effect of multiple losses represented by transitions in education, housing, clinical supports may result in young people needing mental health counseling and supports to manage so much transition and bereavement in such a concentrated period.

For perinatally infected youth who had not envisioned or planned to live long enough to experience adulthood, some who have lost one or both parents to AIDS, the sudden thrust of a normal (if occasionally tumultuous) transition into an adult life filled with adult responsibilities can be isolating, unexpected, and understandably daunting. Transition planning should encourage these youth to express their anxieties and plan for these new opportunities for living, encourage youth to foster their own support network to reduce feelings of isolation, and to operate with the expectation that they may continue to *live* with HIV, rather than die from AIDS. Supporting youth in their further development of resiliency and protective factors begins with fostering youth's belief in their own self-efficacy in crafting a self-determined life beyond their identity as an HIV positive individual or a victim of HIV infection.

ADDRESSING YOUTH CONCERNS

ADOLESCENCE AND YOUNG ADULTHOOD

Adolescence is the transitional stage of growth and development between the dependency of childhood and the independence of adulthood. It is characterized by development of greater social autonomy, differential personal identity, wider social and personal relationships, growing biological and sexual maturity and increasing cognitive knowledge and

competence (Lyal, 2003). Basic tenets of adolescence find youth experiencing a sense of immortality and invincibility. Risk taking, sex and drug experimentation, challenging authority, and a preoccupation with body image are all normal adolescent behaviors. Adolescence and young adulthood is a time when young people are discovering their identity, personal values independent of their family, and developing their autonomy and independence. While it is a stage in which challenging authority figures is rote, it is conversely a time when peer message, influences and pressures also resonate. It is a time of learning, sharing and experiencing intimate relationships and friendships (Birnbaum, 2008). In the characteristics described, HIV positive young people are not any different than any other adolescent or young adult.

As much as HIV positive youth have distinct characteristics specific to them, these youth also experience the same cognitive, developmental and emotional challenges of all adolescents. They need emotional support to promote quality of life and treatment adherence. They need food, shelter, transportation, mental health support, and even child care (e.g., in support of HIV positive young mothers with children) in some instances just to be retained in care and adhere to treatment. After all, it is difficult for anyone, young or old, to prioritize even the more

critical of illnesses when their basic human needs are not being met.

Some youth need assistance addressing their alcoholism and chemical dependency through harm reduction education, motivational interviewing, and introduction to substitution therapies and recovery services. They also need to be able to identify and manage crises and chronic health issues such as suicidal ideation and depression. HIV infected youth need the skills and self-efficacy to successfully navigate benefits, government entitlements (e.g., SSI, Medicare/Medicaid, Ryan White, etc.), and multiple systems of service. Positive youth need peer and clinical support to maintain treatment adherence and secondary HIV prevention goals. They need mentoring in how to assess and expand healthy and positive social supports, conducive to physical longevity and mental wellness. Clearly, HIV positive youth come bearing a host of needs and concerns necessary to overcome to achieve optimal health outcomes. Any one of these obstacles to health maintenance is individually daunting. Now, imagine tackling all of these issues simultaneously only without the average adult's neurological capacities (ABA, 2004; PBS 2002) or life and educational experiences. Yet, it is what is expected of HIV positive adolescents and young adults by service providers and even the young people themselves everyday.

SEXUAL AND REPRODUCTIVE HEALTH EDUCATION

Though HIV positive youth are already HIV infected, they still need to be educated about sexual and reproductive health. Basic sex education that comprehensively addresses STIs, condom use, refusal and sexual negotiation skills are necessary. For young HIV positive women, the need for sexual and reproductive health education, including education on routine and emergency contraception, annual cervical exams (cytology) and STI screenings, and fertility and pregnancy options is essential to their sexual health and wellbeing.

Additional information specific to the secondary HIV prevention needs, issues, and necessary supports for HIV positive youth are included in the appendices of this document.

For additional information on secondary prevention (also known as prevention for positives), providers should access the website for the Centers for Disease Control and Prevention (CDC), <http://www.cdc.gov/hiv/>.

For secondary prevention interventions approved by the CDC, visit www.effectiveinterventions.org.

DISCRIMINATION ISSUES

Like other young people, HIV positive youth may experience discrimination issues related to the age, gender, sexual and gender identity, and socio-economic status. Some youth's economic circumstances are based on social identity factors beyond their control and should be discussed and planned for as part of

transition. Homeless and transient youth who may have been forced into independent living situations for survival because of their social identity, health status, or circumstance may also find themselves engaging in criminal activity, such as survival sex work for food, housing and other basic necessities (Advocates, 2007; NCH, 2008). It is also important to recognize that youth still experience ageism in employment and housing, with employers favoring more mature and presumptively “dependable” candidates and landlords favoring families and older adults assumed to be better stewards of property and able to meet their rental obligations than adolescents and young adults. Housing and employment discrimination may be compounded by a prospective employer or landlord's knowledge of an infected youth's HIV status because of enduring societal stigma, ignorance of employment law protecting disabled persons employment rights, and myths concerning viable routes for HIV transmission. Alarmist news stories of HIV positive workers, employed in positions where there is potential for on-the-job blood exposure, have consistently found employer ignorance to be persistent in those fields where youth are most eligible for employment (i.e., food preparation, manual labor, etc.). Therefore, it is important that the fiscal and educational aspects of consumers' lives, particularly those clients most vulnerable and least prepared for self-sufficiency, be part of a comprehensive approach to transition planning. Chronic

economic issues such as struggles in maintaining sustainable housing are co-factors in client willingness to be retained in care and should certainly be taken into consideration as barriers to effective transition. Housing is particularly important for HIV positive youth, as young people in safe, stable housing are more likely to follow drug regimens and to remain healthy.

Organizational capacity to provide clients with referrals and/or access to programs offering workforce development trainings and apprenticeships, college or vocational planning, and assistance in completing applications for post-secondary education or educational enrichment services, in addition to familiarity with housing systems and eligibility requirements for accessing HOPWA and other supplemental or voucher-based housing programs were core elements of effective transition plans. Youth also need to be educated on their legal rights to work under the American with Disabilities Act (ADA) and for those rights covered under Occupational Safety and Health Administration (OSHA) regulations. A primer on federal policies protecting HIV positive individuals' legal rights to work is included as a reference resource in the appendices of this manual. Landlords receiving supplemental supports through local and federal housing programs, like HOPWA, may even have further entitlement mandates protecting HIV positive youth from housing discrimination. Youth should be encouraged to

report employment or housing discrimination based on age, race, or ability (and sexual orientation or gender expression depending on city or state law in your jurisdiction).

For youth transitioning into adult programs, some adult provider facilities also provide wrap-around services, program referrals, and economic counseling related to employment and housing, but—depending on client demand and the level of available resources to support such programming—access may be tenuous, inconsistent, and not particularly “youth-friendly.” When compared to pediatric and adolescent providers, youth often find that clinical care providers for adults typically receive much less funding with which to provide wrap-around services (DHHS, 2007). Higher patient loads typical of adult care providers may make it difficult to establish the personal bonds on which youth may have come to depend. At some programs, during the transitional phase, youth programs continue to offer comprehensive social and medical services while also attempting to identify supplemental adult providers for service components missing at the adult facility the youth client selected for care transition. Proper planning, exploratory visits, supported referrals (referrals filled with accompanying youth clinic staff), and even psycho-social alumni support can vitally assist a client's successful transition. Managing transition into adult ancillary services while youth are still accessing youth services, where close monitoring, mentorship

and attendance of a known and trusted provider, is one of the key best practices to ensuring comprehensive care following transition.

GENERAL YOUTH CARE, ACCESS AND QUALITY SERVICE CONCERNS

In an effort to address the various challenges and unique characteristics of the HIV positive youth population, basic youth development and service needs may get overlooked. General quality of care for all clients is only a starting point in delivering health services to adolescents and young adults. More permissive adolescent-centered services may be transitioning and preparing youth for more restrictive adult services, but while clients are still accessing youth services there is a need to be youth sensitive and to retain clients in care.

The following checklist are basic quality of care and service offerings for programs successful at establishing and maintaining a youth-friendly environment and retaining youth in care, support and treatment services:

- Flexible service hours, including weekends and evenings
- Walk-in appointments
- Public transportation accessible, transportation or fare cards offered
- Intensive case management with strong referral mechanisms
- Incorporates youth involvement

- Cosmetically establishes a youth oriented environment, with resources and environmental markers specific to the youth population served
- Materials are available in the languages and literacy levels of the youth served.
- Helps young people adjust to their HIV status
- Provides a continuum of care either directly or through referrals with other youth friendly agencies

Life skills education is also a key educational or youth service component for helping youth with transition. Most life skills education processes use an asset-based approach, one focusing on youth strengths or what youth do “right,” and identifies what youth know about a particular subject without assuming youth lack any skills in or awareness of the topic. Life skills education can be provided during one-on-one case management sessions, through mentorship programs with volunteers or long-term survivors, or during group sessions with HIV positive youth. Life skills education topics should include: hygiene, nutrition, physical and mental wellness education, communication skills (including writing and literacy skills), financial education, anger management, stress management, substance use education, youth and health legal rights education, navigating health care systems, and workforce development (including interviewing, resume writing, and employment retention skills).

Agencies lacking the capacity to provide life skill education services partnered—or developed strong referral mechanisms—with local youth development service agencies. To maximize youth outcomes and foster a positive youth experience at the partnering or referred agency, clinical providers usually provided staff capacity building education to the partnering agency about HIV positive youth issues and concerns, ensuring a more receptive environment to HIV positive clients.

While the most successful programs adhere to some or all of the general adolescent care practices described, for the purpose of easing transition, programs educate youth on the general differences between youth and adult service providing agencies to assist in managing youth expectations. As noted by Dr. Birnbaum, there are several striking differences between adult and youth service providers that youth should be reminded of several times throughout the transition process (Birnbaum, 2008). Those differences are varied and may include:

ADOLESCENT PROVIDERS	ADULT PROVIDERS
Offers teen centered, multi-disciplinary care; provider may have minimal to no relationship with parent or caregiver	Adult oriented care based on a stricter medical model
Primary care approach is integrated into HIV care	Adult providers more likely infectious disease specialists than are pediatric or adolescent providers
Youth often do not disclose HIV status to family	Young persons transitional issues usually not given any systematic specialized focus
Issues of confidentiality and consent; care usually offered in discreet, teen-friendly and intimate setting	Clinics tend to be very large and easy for transitioning patients to drop out of care unless very motivated
Teen services core to clinic—sexuality, pelvic exams, STI screenings and treatment, reproductive health, substance use, rights to confidentiality and consent, treatment education and treatment approaches	Adult providers less likely to offer wrap around services including eye, dental, mental health, gynecological screenings, or case management of entitlements

During the transitional phase, case managers also often accompany youth clients on several scheduled visits to prospective adult-serving agencies as another strategy for managing youth expectations and anxieties of adult services. Surveyed programs found that

providing a range of provider choices and program options from which youth can select preferred agencies helps those youth feel more empowered and comfortable with the transition process.

COMMON CHARACTERISTICS OF EFFECTIVE CARE PROGRAMS AND TRANSITION PROCESSES

Among those providers who effectively serve HIV positive youth clients there are commonalities and core elements which consistently emerge in the literature and as trends in the survey data conducted with providers. Settings may differ but there are optimum best practices that have proven to result in quality care, solid youth retention, and

effective transition. The chart on the subsequent page offers a checklist of commonalities many effective programs share. While some elements are germane to clinical settings with case managers, there are practices presented that other types of programs and settings can incorporate to improve the transition process for their clients.

EFFECTIVE PROGRAMS MANAGE HIV TRANSITION PROCESSES BY:

- Maintaining an asset- or strength-based approach
- Being age and developmentally appropriate
- Being client-centered and sensitive to client readiness
- Discussing transitions early
- Creating transition plans
- Creating a plan to meet transitional issues of pregnancy and motherhood
- Being as chronologically flexible as possible in applying agency transitional guidance (i.e., client-centered)
- Encouraging and facilitating independence among youth
- Having a health care provider supervise transitions, preferably supervising a multi-disciplinary team
- Addressing young people's knowledge of both their HIV status and sexual health issues, creating secondary prevention plan and documenting progress with plan adherence
- Conducting personal provider self-checks to ensure the provider attachment is not the barrier to transition
- Partnering with parents or caregivers, when possible, to ensure coordination of "letting go" by caregivers
- Progressively moving clients through transitional benchmarks related to increasing responsibilities & autonomy
- Offering, as possible, a multi-disciplinary team approach to youth care during transitional years
- Fostering youth inclusion in health care discussions and eventually in clinical decision making
- Recognizing the individual needs, abilities, experiences, beliefs, and expectations
- Respecting and accommodating the cultural views and sexual diversity of clients
- Providing an open, non-judgmental environment where youth can work through their fears and anxieties and articulate expectations

- Ensuring simultaneous transition of mental health and case management with transition of primary care
- Defining, documenting and reviewing outcome measures and success indicators throughout the process
- Offering multi-disciplinary training for adult providers in dealing with long-term survivors of perinatal HIV
- When necessary, built the capacity of adult providers through training and technical assistance follow-up to ensure collaborative partnership and uninterrupted continuum of care for the client
- Has trained staff familiar with practical application of adolescent development theory in care and service
- When possible, provides a detailed medical and social history of childhood illnesses (including the youth may have been too young to remember), discussions, and social concerns in a detailed summary to the adult provider

MODELS, PRACTICES AND APPROACHES

APPROACHES TO AGE AND DEVELOPMENTAL READINESS

Most transitions create anxiety for the health consumer. Therefore, timing of the transition will depend on developmental readiness, complexity of the health problems, characteristics of the adolescent and family, and availability of skilled adult health providers (Reiss, 2002). Repeatedly surveyed programs stated that transition should primarily depend on the readiness of the young person. However, nearly all of the surveyed programs have a stated transitional age in which clients must matriculate to adult services. Only two programs surveyed allowed young people to access services through their program past age 24 and only one allowed service access past age 27, though several offered opportunities for young adults to return to mentor young survivors.

There is a tension between when youth may be ready to begin the transition process and the age in which responsible transition is mandated. To avoid any such tension, some programs plan for transition with the adolescent from day one. All surveyed programs effectively transitioning youth consumers into adult care include a written progressive process that clinicians and service providers are expected to utilize as a guide for transitioning youth. As a best practice, the transition protocols are reviewed at least once every two years to ensure relevance and for potential changes based on lessons learned during implementation and to reflect changes in the youth demographics. The protocols are generally broad in language, but include clear benchmarks. The following models are age-appropriate, developmentally specific guidance protocols promoted by programs with demonstrated effectiveness in transitioning youth:

THE PARTNERSHIP FOR FAMILY HEALTH NORTHERN MANHATTAN HIV CONSORTIUM MODEL FOR POSITIVE YOUTH TRANSITION INTO ADULTHOOD

AGE GROUP	8-12	13-16	17-19	20-24
ISSUE AREA	Medical and Mental Health			
SELF-ADVOCACY	Encourage caregivers to disclose to child. Solicit direct conversation with adolescents; increase private meetings with adolescents	Assist adolescents with a calendar of appointments and prescriptions.	Enforce responsibility in making and keeping appointments; Provide copies of medical records and forms of identification.	Prepare youth with substantial medical and entitlements history.
SELF-CARE	Begin to explain medication, deal with early adherence issues; links to support groups and/or counseling	Ensure adolescents understands diagnosis, needed medications, health precautions; Connect to teen-based adherence program.	Review medical history; promote questions about care regimen and possibilities for future changes in regimen.	Help identify appropriate adult providers through visits to new clinics; Transfer medical records to new provider; highlight key issues.
ENTITLEMENTS	Working with parents or caregivers and foster care systems to ensure they are taking advantage of entitlements enrollment	Working with parents or caregivers and foster care systems to ensure they are taking advantage of entitlements enrollment	Access ADAP, Medicaid, with adolescent participation. Obtain personal identification (i.e., state ID, etc.)	Encourage adolescent to pursue cash assistance opportunities such as SSI/SSD; Transition to Family Health Plus; Apply for independent housing assistance.
GUARDIANSHIP / PERMANENCY PLANNING			Determine guardianship status	Ensure adolescent is aware of and has documents in place for Health Care proxy and Advance Directives

AGE GROUP	8-12	13-16	17-19	20-24
ISSUE AREA	Personal and Social Choices			
CAREER	Initiate conversation about future goals	Promote volunteer and peer educational opportunities with connect non-profits	Connect youth to job training; Explore post high school options, vocation/education, college	Document long-term education and career goals
SEXUALITY	Facilitate Questions; Assess "Sexual Knowledge" base	Link to adolescent friendly gynecologist, begin to review sexuality issues and safe sex practices	Continue sexuality conversation; Encourage questions about HIV positive sexualities, pregnancy; Refer for regular sexual health check-ups	Continue sexuality conversation; Encourage questions about HIV positive sexualities, pregnancy; Refer for regular sexual health check-ups

SOCIAL NETWORK	Connect to social events, summer camps, and support groups; Pair up with older mentor	Promote after school activities; Ensure support networks; Sustain healthy relationships	Promote after school activities; Ensure support networks; Sustain healthy relationships	Support mentorship of a younger HIV positive adolescent.
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adapted from *Positive Transition to Adult Health Care* developed by the Northern Manhattan Transition Consortium

The Consortium transition model is concerned with referrals to medical and mental health services and encouragement of healthy decisions regarding nutrition, sexuality and substance abuse. The model presents a mapped transitional timeline focusing on the

progressive establishment of new boundaries and imminent transition into adult services.

An age-based international model out of the UK, outlined by Dr. Hermoine Lyall and Dr. Diane Melvin, offers a step-by-step transition plan for implementation in a medical context:

11-13 YEARS OLD	13-14 YEARS OLD	15-16 YEARS OLD	16 TO 18 YEARS OLD
Review of young persons knowledge: Do they know their HIV diagnosis	Transition plans started with discussion with young person and parent/care giver (Record made in notes)	Update transitional care plan with young person and caregiver (Include any concerns specific to young person or family influencing timing of future transfer or further assessments or referrals needed)	Suggested age ranges for completion of transition steps
Discuss changes in development (e.g. puberty)	Young person offered some individual time with pediatrician and nurse. Update of HIV knowledge provided, including HIV management and treatments, transmission. Responsibility for health treatments shared between young person and caregiver.	Gather client and caregiver views and discuss possible places of transfer (arrange informal visits) Young person meets with worker from adult clinic (physician or clinical nursing staff); if possible meeting should commence in a familiar setting or with someone from pediatric service	
	Confidential talks on sexual relationships and sexual health (by adult service provider).	Discharge summary completed and discussions with receiving clinic completed.	
	Discussions on independence and self-management of medicines	Transfer/leave final meeting with young person and caregiver.	

Adapted from *Supporting Change: A Successful Transition for Young People grown up with HIV Infection* (Dr. Melvin, 2008) and *Growing Up, Gaining Independence: Principles for Transition of HIV Care* (Lyll, 2003).

This medical model advocates for a multi-disciplinary approach to transitioning youth to adult care, focused on multiple, age-appropriate discussions and an understanding of the community, educational and voluntary services available to play a role in supporting wider aspects of adolescent needs. For transitioning youth to adult care, the following

outlines the key discussion recommended by age range (Lyll, 2003; Melvin 2008):

Younger Adolescence: (Ages 11 to 14)

- Focus is on knowledge and understanding of diagnosis including the level of disclosure

among family, social, educational and clinical networks.

- Explanations updated about medications and routes of transmission
- Discussions of puberty and sexual development
- Issues related to adolescent development—increasing responsibility, initiating independence, choices and consent.
- Changing relationships—in family, with peers, etc.
- Addressing concerns about support for parent(s) or caregiver(s) during transition.

Middle Adolescence (Ages 13-16)

- Focus on sexual health and relationship prevention of HIV transmission
- Discussions of wider disclosure and confidentiality issues—who needs to know and how to negotiate disclosure.
- Addressing increasing independence and responsibility for self and how to take more control of health. Medicines should still be a shared responsibility between youth and caregiver
- Peer support network identification
- Role of support agencies for adolescents in general and those HIV specific

- Managing specific or individual needs—other disabilities or difficulties
- Plans for future: school, college, support, career, relationships

Older Adolescence (ages 15 and older)

- Focus on preparation and support for transfer to new service (adolescent or adult)
- Discharge summary and identification of specific services needed by individuals reviewed with young people
- Focuses on future plans—education, employment and housing.

As basic principles, this model encourages flexibility in determining the most appropriate chronological age for starting or having each of the outlined transitional discussions. A slower transition is recommended depending on a client's cognitive and learning abilities, changes in care providers, and serious illnesses within the family. Transition is generally not recommended for youth at end-of-life stages or during acute serious illness. Providers are instructed to regularly provide a forum to hear the young person's views at key stages in treatment and service development. Providers are to also record the transitional phases and conversation outcomes summarizing transition for fellow and future providers in a summary document. Youth in this model are encouraged to have increasingly greater autonomy, independence and responsibilities for the

management of their own health care and participation in health care choices with each year of transition, making for a more seamless process right from the start. When possible, the model outlines multi-disciplinary case conferences between adult and adolescent providers as a recommended best practice.

MODELS OF BEST PRACTICES, PROCESSES AND PROCEDURES

Two HRSA recommended community based program models for transitional youth agencies to consider for replication are the Ruth M. Rothstein CORE Center in Chicago (The Core Center of AMAC) and Larkin Street Youth Services (DHHS, 2007). The tables below provide an overview of AMAC and LSYS basic model for successful youth transition:

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 two 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 the capabilities of adult care providers to treat transitioning youth. 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.

This amended table was adapted from *HRSA CARE Action: Transitioning From Adolescent to Adult Care* (DHHS, 2007)

THE LSYS APPROACH

LSYS is a community-based organization addressing homeless youth needs. 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.

This amended table was adapted from *HRSA CARE Action: Transitioning From Adolescent to Adult Care* (DHHS, 2007)

Children's National Medical Center (CNMC) of Washington, DC is a children's hospital renowned as a pioneer in providing clinical services for children, youth and families with HIV and AIDS. The Burgess Clinic of CNMC was developed in 1989 to manage the unique medical needs of adolescents ages 13 to 21. While Burgess is often the primary care provider for DC youth from infancy through young adulthood, the clinic also partners with six youth community-based youth organizations who provide six months of care advocacy to newly diagnosed clients to link and maintain clients in services at Burgess. A

team at Burgess is responsible for transitioning youth into adult care, though a case manager is responsible for key elements of the practical implementation. In their work with youth, CNMC follows the AMAC multi-disciplinary approach with a team of nurses, physicians, mental health professionals, social workers, nutritionists, volunteers, coordinators and other specialists as needed. Unlike the LSYS program, transition to adult care begins when a client reaches 20, a full two years before maturity. The following is a month by month case manager plan for youth transition:

AGE GROUP	AGE 20	AGE 21
MONTHS 1-3	<ul style="list-style-type: none"> • Introduce transition plan • Explore youth feelings about transitioning into an adult facility • Identify and address any expressed fears; continue addressing throughout the process 	<ul style="list-style-type: none"> • Continue evaluating and processing with client the first visit with the physician • Schedule final medical appts., including: eye, dental, dermatology and gynecological • Encourage client to check in with the new adult physician accompanied by the case manager
MONTHS 4-6	<ul style="list-style-type: none"> • Discuss list of transition facilities • Assist client in making preliminary choices (consider insurance and transportation issues) • Involve parent or significant other 	<ul style="list-style-type: none"> • Second visit to new physician with out the case manager • Evaluate and process second visit with client
MONTHS 7-9	<ul style="list-style-type: none"> • Notify case manager of three preliminary choices for providers • Identify and work through potential insurance, entitlement, and transportation issues • Visit all three preliminary choices for adult providers, all visits accompanied by case manager (Month 7: visit first adult provider candidate; Month 8: visit second adult provider candidate; Month 9: visit third adult provider candidate) • Make appointments and arrange insurance with client; schedule appointments; send medical records 	<ul style="list-style-type: none"> • Complete final medical appointments at the youth clinic • Send final medical records • Encourage client to check in with new case manager and physicians • Encourage clients to check in with ancillary services (e.g., eye, dental, mental health, etc.)
MONTHS 10-12	<ul style="list-style-type: none"> • First official visit to the selected physician (accompanied by case manager and parent or significant other, if possible) • Schedule second visit with physician • Identify and arrange services not provided at new facility (including eye, dental, dermatology, mental health, case management) • Schedule next appt. at youth clinic 	<ul style="list-style-type: none"> • Month 10: Visit to new physicians, follow-up call by case manager and with physicians • Month 11: Case manager follow-up call to client • Month 12: Case manager follow-up call to client

Amended table is adapted from the *Children's National Medical Center Burgess Clinic Procedural Guidance*

The University of Miami Miller School of Medicine model offers a more graduating phased approach to youth transition.

Phase One	<ul style="list-style-type: none"> • Formally begins at age 23 • Identify clients appropriate for transition • Discuss with client the need to transition • Reminder of the original intent expressed earlier for transition
Phase Two	<ul style="list-style-type: none"> • Begins at age 24 • Client meets with adult infectious disease physician for the first time • Social work team provides on-going assessment of the client's readiness for transition
Phase Three	<ul style="list-style-type: none"> • First check-up on adult infectious disease physician in adult care setting • Follow-up appointment with adult infectious disease physician in adult care setting • Adult infectious disease appointment scheduled at conclusion of follow-up visit • Ongoing psychosocial support from medical team, social workers, peer educator/advocates,
Phase Four	<ul style="list-style-type: none"> • Reminder phone call made to client before adult ID appointment • Client attends first appointment at adult provider accompanied by peer educator for support • Social worker continues to follow client for psychosocial needs • Medical chart officially closed in adolescent care setting
Phase Five	<ul style="list-style-type: none"> • Qualitative in-depth interview conducted to solicit anxieties, apprehensions, and fears the client may have experienced • Feedback reviewed by the adolescent pediatric and adult health care teams • Adolescent care social workers continue to provide ongoing adherence counseling and support for one year • Psychosocial chart officially closed in adolescent care setting

Adapted from Dr. Lawrence Friedman ppt., *Movin' Out: A Transitioning Model for HIV-Infected Adolescents Entering into Adult Care*

CAMP PROGRAMS

According to the American Camp Association, in 2005 there were 26 special needs camps specializing in serving children with HIV/AIDS. These programs serve both perinatally and behaviorally infected youth. The age

segmentation of camps generally find younger youth at camps to be perinatally infected and older youth to be behaviorally infected, though that dynamic is changing with the aging of perinatally infected adolescents into adulthood. Nearly all of the programs serve both infected and affected youth alike. The racial and socio-

economic composition of campers is identical to those of youth clients accessing clinical and social services (though there may be more youth from rural areas than what is found in most clinical programs, nationally). Sexual identity issues may be more pronounced in camp settings among behaviorally infected youth, given the disparity in new HIV infections among young men who have sex with men compared to the largely self-identified heterosexual perinatally infected population. Camp programs serve youth as young as 7 and as old as 18, not including young adults kept on as senior campers or alumni that become camp counselors (up to age 24). Surveyed camps depend heavily on volunteer support and serve a mix of urban, suburban and rural youth.

Camp programs specifically for children with special needs can already be ahead of the game in their ability to help youth access the tools and skills those young people will need to successfully transition into adulthood. Camp programs for youth with special needs are by their nature “client-centered.” Camp programs are “asset-based” in their positive youth development approach, focusing on what youth can do, rather than on a child’s limitations. The core mission of many special needs camps is to “allow children the opportunity to be children,” with the disease of a young person playing a secondary role in address. While youth are given opportunities to engage in outdoor competitions, arts and

crafts, and other basic camp activities, there is also an emphasis on building childhood independence and fostering a responsibility to fellow campers. Problem-solving is not only encouraged, but modeled by camp counselors trying to creatively provide the widest range of experiential learning and recreational opportunities possible to campers despite potential barriers presented by a child’s disability.

Those camp programs that are adhering to the standards outlined by the American Camp Association (ACA), the national association of accredited camp professionals, are providing the high quality, comprehensive services to youth that mirror those that youth should be able to access in their home community. Sometimes the services youth receive in camp are better than those available in their local community, particularly for rural youth. Arguably, camp programs are uniquely positioned to help youth transitioning into adulthood. Programs unique relationships with youth who annually return for an empowering experience that holds them to the same expectations of any other child has already created the proper environment—and laid the necessary psycho-social groundwork—for transition education.

At camp, youth expect to be full, active participants in their experiential learning and development through activities that challenge their assumptions about their abilities and

liabilities. This is dramatically different than what youth can come to expect from their clinical and social service settings, where they are catered to as “different” or where youth may perceive themselves to be—and are more likely to be tolerated operating as—more passive actors in their own development. While every clinical setting or social service agency does not coddle their youth clients and every camp is not necessarily meeting their goal of fostering youth independence and responsibility, the expectations of a given context cannot be underestimated in their impact on youth outcomes.

Some hospitals and other clinical settings have created camps or partnered with existing camps, understanding the power of taking youth outside of their home environment for experiential education opportunities for their clients. Camps with strong clinical ties, or who are themselves an outgrowth of pediatric and adolescent clinics, are among those best able to ensure continuity of care and cross-agency communication for continual case management. In such cases, a youth client’s developmental progress at camp becomes a seamless part of their case record and is built upon in subsequent case management interventions.

Given their many environmental and developmental benefits for youth, camp programs may represent a great opportunity to introduce or further develop elements of youth

transition into adulthood, but it is an underutilized opportunity. Many camp programs do not actively engage in transitioning youth into adult care, sometimes seeing their role as purely one of a camp, not that of a case management social service agency. Yet, there are a couple of fine examples of camp programs pioneering youth transition into adulthood and adult care using four main strategies:

- Partnering with those agencies where campers are receiving clinical and social services in their home base, mostly through referring case managers.
- Providing progressively more challenging life skills education, goal setting and future planning opportunities through a separate older youth track at annual camp visits.
- Providing leadership training and service learning opportunities as elder or senior campers at camp.
- Providing workforce development training with opportunities for employment as fully trained camp counselors.

Camps that are using these strategies often employ a combination of these approaches. Camp programs working with older youth create leadership or camp counselor tracks for high school aged youth distinct from their younger, elementary school-aged camp track.

In doing so, camps with leadership or camp counselor tracks essentially mandate many of these developmental opportunities as camp participation requirements, thus ensuring that their youth alumni have the necessary skills, resiliency and protective factors to face the world as independent, empowered adults aware of their capacities and prepared to make a contribution.

Not all camps approach youth preparation to self-determination and self-sufficiency the same way. Approaches and program designs vary based on the resources and reach of each camp. The following camp programs employ variations of these best practices and present a snapshot for what strategies other camps could consider as they determine their role in preparing youth for independence.

<p>Camp Name: Camp Kindle Age(s) of Youth Served: 7-15, 16-18 Location: Hordville, Nebraska</p>	<p>Older youth receive education in three core areas: Health Education, Life Skills, and Team Building. Leaders in training (LIT) and counselor in training (CIT) tracks are offered as transitional education, potentially as two-tiered training for long-standing youth, LIT for youth ages 3-15, CIT for youth ages 16 to 18. Special retreats on transition issues are also offered. Both a psycho-social team and behavior management team are in place to work with youth during camp sessions for mental health issues. An effort is made to work with referring social workers on youth cases.</p>
<p>Camp Name: Camp Hope Houston Age(s) of Youth Served: 13-24, 7-15 Location: Houston, Texas</p>	<p>Youth age out at 15 and after a year can return as camp counselors in training. During the year out of camp, older youth can attend the Universal Teen Program, a life skills and leadership development program, set on a college campus. Change of venue from the camp is recommended to reinforce transition message. There are no recreation opportunities offered during this transitional phase. Youth develop five-year plans for college or workforce entry. Education focuses on self-sufficiency and making distinctions between entitlement and empowerment. Mental health services are provided to address behavioral, psycho-social and family issues. Youth who complete the teen training program are rewarded with new opportunities in the camp counselor-in-training program.</p>
<p>Camp Name: Camp Amerikids - Leaders In Training Program Age(s) of Youth Served: 7-17, 16-17 (LIT) Location: Warwick, New York</p>	<p>Aging-out youth are channeled into the Leadership in Training (LIT) program. LIT is a two-year youth development program. Youth graduates of LIT are still retained as alumni, including alumni activities such as dinners, day trips and other events. LIT grads are also offered training and mentoring opportunities to become junior counselors. Activities are changed from year one to year two of LIT to keep program fresh for campers. Wellness program supplement is included to provide mental health and treatment adherence support. Relationship maintenance with other organizations supporting youth is the key to their transition strategy and retention success. Referring social worker is the point of contact for youth to help manage merging issues.</p>

As one can observe, shared characteristics of

each program include mental health support to

address youth psycho-social counseling needs, a graduating scale of increased opportunities for additional leadership training and responsibilities, up to and including employment with camps in a formal capacity as counselors. There is a heavy emphasis on separation from younger youth “camp” programming, in some instances moving the older youth program to a different space entirely to mark the change. At least two of the programs require youth to take a year off from the traditional camp program as a kind of rites of passage into the more mature program, with elevated expectations and responsibilities in their new setting.

All are asset-based programs and some have incorporated elements of the Search Institutes’ *40 Developmental Assets* advisory to shape their projected outcomes and inform their leadership development trainings. All of the programs provide specialized training to staff working with older youth to reinforce the focus on adult preparation over recreation. Outside of adhering to the ACA standards, the most successful programs are self-made, using a more fluid design than the clinical models outlined earlier. These programs have had no manual or training guidance to operate from in developing their strategy or cultivating their staff training for leadership- and counselor-in-training programs. Though they vary in the level of evaluation they require, including focus group and individual client interviews, at a

minimum each program monitors client progress and outcomes through client surveys.

MEASURING SUCCESS

EVALUATION AND PERFORMANCE MONITORING

How do you know that your transition protocol or process is effective? How do you measure whether your client transitions are a success? Certainly, follow-up calls once the client has transitioned or still meeting with the client formally or informally during the first year of transition are a couple of obvious ways to monitor individual client success, but it won’t measure the overall program or processes effectiveness or assist in making improvements. Evaluation of the transition process or model designed should be regularly conducted to identify improvements that can be made in process, policy and procedure. In addition to the care clinicians, social workers and other support staff involvement in client transitions, evaluation of the transition process should include youth, parents, significant others and other stakeholders to identify potential issues and recommendations for continual program improvement. Evaluation of the process should include both quantitative and qualitative measures. Elements to consider for monitoring your agencies transition process should include:

- the appropriateness of the selected age for transition,

- the number steps and activity for each step of transition,
- quality of referral linkages and partnerships,
- client satisfaction,
- client treatment adherence
- client retention in care, support, and ancillary programs during the transition process
- client retention in adult services six months following transition
- medical regimes, number and changes of combinations and any adherence concerns
- sexual or reproductive health issues, including pregnancy
- youth involvement in their medical and mental health care
- youth ability to navigate health systems
- youth ability to navigate institutional support networks
- new incidence and treatment of co-morbidities during transition
- new diagnosis and treatment of chronic illnesses and opportunistic infections
- initiation of and/or retention in mental health counseling and treatment
- youth ability to set goals and fulfill tasks leading to goal achievement
- youth ability to maintain secondary prevention risk reduction plan
- youth ability to maintain harm reduction plan or initiate and maintain drug abstinence
- youth maintenance of medical appointments and time management in obtaining service

EVALUATION CORE ELEMENTS

What about during the transition itself? To determine whether you are continually moving a client along a spectrum of benchmarks toward transitioning out of youth services, evaluation, monitoring and documentation are the stuff of quality programming. A multi-disciplinary working group of representatives from both the adolescent sexual health and adult health services should regularly meet to evaluate client progress during transition. Program administrators and line staff responsible for evaluation and performance monitoring should consider the systematic recording and monitoring of the following outcomes and critical elements when designing their evaluation plan:

- the needs and views of people and their progress throughout the process
- cognitive or developmental changes and challenges

Impact and process evaluation markers, both qualitative and quantitative, should be clearly identified. Baseline should be established at client intake. Agency client intake tools may need to be refined to complement the specific goals of the client's transition plan. Subsequent

client progress should be closely monitored by teams at both the youth and adult facility through regularly scheduled, joint client evaluation meetings. Quarterly, annual, and bi-annual program performance evaluation activities should be coordinated for quality assurance, protocol adherence, and to measure staff responsiveness to client needs. Regular performance review can assist administrators with early identification of client and staff performance issues to better ensure quality service, coordinated problem solving, and determine any necessary changes to client approach. Client satisfaction surveys and qualitative interviews with youth clients and core transition players should also be facilitated to annually capture lessons learned, qualitative data about client experience, and recommended strategies by youth and stakeholders before they transition out of your services—helping future clients to benefit from their knowledge and experience with the process. Final review of client’s medical and psychosocial clinical charts should also be reviewed and noted for evaluation purposes before transition of the medical records to the adult provider. Finally, evaluation tools and tracking mechanisms will need to be formulated to reflect the outputs and outcome goals of the transition plan and protocols that your agency designs.

GETTING STARTED/ CONCLUSION

Now that you have a complete overview of issues, programs, potential models, best practices and approaches to transitioning youth into adult care, it is time to get your own organizational plan started. So roll up your sleeve, gather your team and let’s review your action steps for getting started.

GETTING STARTED WITH YOUR ACTION PLAN

First, you’ll need to set up a meeting with your core team to discuss how youth are currently being transitioned at your agency. Identify the core elements and action steps of your transition activities, and identify gaps in a preferred continuum of care using the information you’ve gleaned from this resource. Are there any practices that are working and should be retained? What has already been tried and failed to work? It is important to talk through staff beliefs about existing transition policies or protocols that may have been informally passed down, assumed, or were officially implemented but are now outdated.

Second, conduct a resource map of adult provider services, resources and funding entitlements available of HIV positive adults in your area. Assess the relationships your agency has with those providers and create a plan for strengthening old relationships and developing new ones. Implement educational brown bags,

young adult transition work groups, workshops, and formal cross-trainings to improve relationships and build capacities at adult provider facilities. Consider creating a collaborative or consortia with area providers to create or reinforce the service network for youth. Generate an online resource directory with named provider point persons that providers can agree to update at least annually. Establish memorandums of agreement or understanding (MOU/MOA) with adult providers and ancillary supplemental services documenting expected scope of work and service, referral protocol, quality control, tracking and monitoring each agency can expect from the other for youth clients.

As feasible, your organization's transition plan should attempt to create "one-stop" shopping internally. Comprehensive services for youth would include: primary health care, HIV specialty care, social service case management, psychological counseling, support groups, prevention education and health promotion, life skills development, community service opportunities, and information on clinical trials or access to research. However, wrap-around services do not have to happen within a single agency, The referral network system you foster through MOUs, trainings and collaborative activities should be strong and staff supported by adult liaisons to youth whenever possible. Referral and adult transition agencies should be familiar and comfortable with the developmental age group (the ages of

transition, whether 19 or 25) and the chronic disease(s) of the referred youth. To improve the number and range of providers you can offer youth as options during transition, identify, train, and create MOUs with the best *adult* care providers offering the most comprehensive services available, not just those local adult providers and referral partners who are already "*youth friendly*"—a potentially limited number depending on your service area.

While cultivating or improving the transition infrastructure for youth externally, there is still much to be done internally at your agency. When establishing a transition plan at your agency, it is important to establish principles of transitioning that provide the foundational support for the established organizational policies, practices and procedures for transitioning. Transition principles identify your agency's approach and philosophy with all stakeholders, while also helping to inform your clients and staff of your organization's expectations. They will also facilitate more guided youth-adult interactions. In addition to practical approach and overarching philosophy, your agency's principles should define transition age, goals, youth and parental inclusion, and definition(s) of success. According to the literature, asset-based and client-centered approaches are the most recommended to ensure the best possibility for success.

In clinical settings, create a multi-disciplinary team with a nurse or case manager guiding individual client transition. Team members can include: physicians, nurses, advanced registered nurse practitioners, social workers, case managers, psychologists, dietitians, and peer educators/advocates. Team members and stakeholders should independently—and then jointly—participate in focus groups and planning sessions to collectively inform protocol development. A multi-disciplinary team should contemplate the possibility of crafting a teen and young adult clinic supervised by an adult physician, and the clinic should operate on days and during hours that cater to young people. Co-located clinic settings should also be considered to expand youth access points to service.

Plans for psychosocial issues of care are essential for transition protocol incorporation. Creating roles for volunteers, mentors and peer advocates is an option for augmenting organization costs and providing additional youth and staff supports within the transition plan. Establish strategies and length of time the client will have access to a social work case manager following and during the final leg of transition. Multiple strategies for support intervention, both in-person and virtual (i.e., on-line), should be deliberated and outlined in the plan. Formulate screening tools and planning tools to implement the multiple goal setting activities outlined in your plan. Incorporate education or workforce

development continuation in the tool as well. Create or find a “life skills” curriculum with incentives for continuation in this developmental component.

Finally, to complete your transition plan protocol, denote indicators of success, benchmarks, monitoring process, client and program outcomes for program evaluation. Schedule at least quarterly reviews of client progress and program concerns to address youth and staff issues as they arise. Review of the final protocol should be implemented at least once every two years, with client satisfaction surveys, qualitative focus groups with team members, youth and other stakeholders occurring annually. Good tracking and monitoring of client outcomes will truly determine the success of your plan.

POTENTIAL ORGANIZATIONAL CHALLENGES AND SOLUTIONS

As with any new program venture or comprehensive procedural changes, there are chances for things to go wrong. Young people are unpredictable and collaborative arrangements between two organizations with differing perspectives on clients and care is fraught with opportunities for miscommunication and mutual frustration. Staff at the youth or adult-serving agency may not always be cultural competent or have philosophically bought into client-centered, asset-based approaches to service. Staff turnover of trained stakeholders in transition

programs, poor cross-agency communication, murky roles and responsibilities, unsubstantiated expectations and misinformation are but a few of the issues that can derail a successful collaborative partnership between transitioning partnerships. Clients not properly prepped about the differences in organizational cultures and philosophies or possible disparities in resources and services may be disappointed and exasperated, making successful transition less likely. The strategy for avoiding these common pitfalls is preparatory planning and on-going program monitoring, the staples of sound and efficient program design.

Preparatory Assessment Activities

Prior to program or procedural implementation, agencies may need to conduct a SWOT analysis (Strengths, Weaknesses, Opportunities, and Threats) with staff and trusted clients to identify potential issues that may arise in the execution of the new transition plan and to properly determine appropriate approaches to the team's identified weaknesses and threats (whether cultural, external, interpersonal, or environmental), while also planning to fortify strengths and capitalize on threats facing the agency's plan. A thorough SWOT analysis can help an agency avoid being caught off guard by issues or concerns before they arise and to prepare a plan of action for each of them. Agencies can conduct a SWOT analysis with resource tools

available on-line or can hire a trained facilitator to guide them through their process.

Quality Assurance and Cross-Communication

Quality continuum of care for youth clients is the result of there being a mutual understanding between referring or partnering agencies about the services both parties offer clients, the resources available for clients and staff to ensure care, and shared information about each organization's policies and procedures in managing client needs (including: retention, adherence and maintenance strategies). Further, agencies partnering or developing strong referral linkages should strongly consider developing a non-binding but mutually respected Memorandum of Understanding or Agreement (MOU/MOA) whose purpose is to express clear roles, responsibilities, and the scopes of service each partner agree to make available to clients under this contract. Preferably, agency partners would maintain a scheduled review of the MOU every six months (or annually at a minimum) to ascertain contractual adherence, keep new and changing staff members informed of the agreement details, and to amend the agreement as necessary to reflect changes in agency service offerings and new scientific understandings of proven models and best practices.

In addition to an MOU, both the adult and youth serving agencies should offer one another a documented up-to-date resource

inventory outlining the menu of resources and services available for youth clients. A gap analysis of the difference between the services young people have come to expect from the youth serving agency versus those available should also be conducted and discussed between partners, to help providers set client expectations about the differences in program services and incentives prior to transition. This again is another strategy for assisting young people in becoming familiar with the variety of agencies' services and approaches to care, support, and treatment so clients can be empowered to make informed decisions about their preferred agency of transition.

Potential Staff Issues

Staff involved in client transition should be assessed for any necessary competency and skills building trainings staff members may need to manage the myriad of challenges youth clients present. Staff ideally would be involved in the creation of on-going staff support mechanisms where staff grievances and discussions are allowed to air any concerns or apprehensions about youth clients and the transition process, without fear of administrative retribution for expressing stress, fatigue or disillusionment. Rather, offering staff peer or even clinical support to explore their feelings about experiences with such unique youth clients. The latter can be especially helpful in avoiding staff burnout with issues that can be emotionally taxing for case workers involved in client retention and case

management. Creating a supportive, non-judgmental environment for those involved in casework can also prevent clients from bearing the brunt of staff frustrations and fatigue in response to poor client outcomes or when system processes operate in a less than optimum fashion.

Staff ill-prepared for client-centered counseling, instead preferring a more authoritarian or client dependent approach as a means of administrative expediency—perhaps unintentionally affecting client care and retention in the process—need to be identified and trained on proven outcomes this approach to care has exhibited with clients. Peer mentoring between case workers and close monitoring by supervisors of client outcomes, retention rates, and satisfaction surveys can assist. In addition to monthly or quarterly team case reviews by the youth providing and receiving agencies, a quality assurance review of staff adherence to approved transition processes and procedures and buy-in to organizational philosophies supportive of client-centered, asset-based case management is key to sustaining quality client care.

Funding Opportunities

Funding and program sustainability are always concerns for non-profit entities, though perhaps heightened in the current economic crisis where nationally foundation endowments are down 20 to 40 percent and federal HIV/AIDS funding has been relatively flat-funded

for a decade. Funders are interested in supporting efficient operations that keep costs low and quality high. Federal and state funders are intensely focused on client maintenance in care and treatment services as a cost-cutting measure and a preventative health strategy for both those who are HIV infected and the presumably uninfected public at large. Clinical environments with demonstrated linkages to a variety of key health and social services, those that can create—either internally or through collaborative partnerships—“wrap-around services” for clients exhibit a maturity and efficiency attractive to donors seeking to fund smarter with diminishing resources.

Organizational collaborations with documented agreements, evidence-based outcomes, and supported referral systems with performance monitoring and evaluation strategies beyond blind, weakly tracked client referrals offer enhanced possibilities for quality care and are better positioned for sustainable funding by larger foundations and government agencies. Therefore, it may be in the best interest for partners to jointly respond to funding opportunities where it makes sense, and submit partnership MOUs in addition to standard agency letters of support (where appropriate) to provide stronger evidence of the safety net agencies have provided for youth clients.

CONCLUSION

Youth transition into adult care is a complicated process that requires simple, yet

intentional strategies for fostering success. We hope the models, practices and recommendations will assist you in designing a process that will help your clients meet their social, physical and psychological needs and sustain in care. To support your efforts with clients, we have provided a number of quick references to help you fill in the blanks of your plan. Our hope is that this reference will assist you in partnering with youth to transition them into quality adult services and adult lives; fortifying them with the stabilizing, empowering information they will need to know and understand along the way. The accompanying youth service provider toolkit offers guidance on disclosure, secondary prevention, treatment adherence, and an overview of the core entitlements and legal protections for people living with HIV and AIDS. There are also a number of websites, hotlines, and recommended interventions listed throughout to assist you in improving your services to HIV positive teens and young adults so that they can positively progress into more secure and responsible adult lives.

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APPENDIX I

Disclosure

Helping a youth client to disclose their HIV status to family, friends, partners and providers can be challenging. Vertically infected HIV positive youth clients may have as difficult relationship with disclosure as those behaviorally infected, but there are differences. Perinatally infected youth may have histories witnessing negative outcomes to disclosure in their parents or siblings lives and be reluctant to consider the positive outcomes from open disclosure. The parents or caregivers of many perinatally infected did not always disclose to their children that the child was HIV positive, much less the parent's own positive HIV status. Some HIV positive youth were lied to for several years about their diagnosis, even while accessing treatment. Too often youth were fed stories about "bad blood" or offered false alternative diagnosis of other chronic conditions such as cancer or diabetes, with some not being honestly informed of their actual diagnosis until a parent's death or nearing the age of transition. There also may have been cultural issues that prevented disclosure related to parental power and authority over sharing a child's medical information with their children. Sometimes there is also resistance among parents to recognize older youth rights to autonomy, independence or an eventual active role in their care and medical decision making.

Behaviorally infected youth, having an even greater sense of invincibility and more likely to be in a state of denial about their infection status, may present even greater challenges for disclosure, particularly for those newly diagnosed. Providers should treat each case differently, based on the client's readiness, willingness, capacities and legal obligations to disclose. Still, providers should have some guidelines, scripts and strategic options ready for assisting youth clients in combating stigma and disclosing their HIV status.

PROVIDERS WORKING WITH HIV POSITIVE YOUTH ON DISCLOSURE SHOULD...

- Keep it client centered and based on client readiness, though offer assistance at regular intervals
- Describe the benefits of ongoing assessment and discussion around disclosure
- Outline a format to help clients with effective decision-making about HIV/AIDS status disclosure, listing the benefits and limitations

- Explain the provider's value of supporting a client's decision regarding disclosure
- Discuss the steps involved in making the decision to disclose HIV/AIDS status to family, friends and service providers
- Identify client fears and role play disclosure scenarios (experiential exercises) with both positive and negative reactions to disclosure to assist client in preparation for both
- Utilize science based intervention processes such as The Healthy Living Project (15 individual sessions) or Healthy Relationships (5 small group sessions) to help walk clients through stigma, self-image and disclosure issues for HIV positive individuals
- Keep referrals on hand to deal with possible legal, mental, and domestic violence ramifications regarding client disclosure
- Support client's physical safety and planning around safety as much as you support and encourage disclosure, to ensure client health and well being is paramount

PROVIDERS SHOULD KEEP A CHECKLIST IDENTIFYING POTENTIAL SOCIAL AND PSYCHOSOCIAL BENEFITS OF DISCLOSURE FOR THOSE PESSIMISTIC CLIENTS. DISCLOSURE CAN:

- Reduce anxiety around transmission of HIV to others
- Lead to greater quality of social support, greater self-esteem and lower levels of depression
- Result in more support in treatment initiation and adherence
- Lead to increased intimacy with partners
- Lead to less risk-taking behaviors
- Help foster a sense of purpose
- Help create or strengthen more social supports among friends and family

- Reduce or eliminate the possibility of legal ramifications for a failure to disclose
- Contribute to the environmental reduction of stigma for HIV positive individuals

DURING COUNSELING SESSIONS, PROVIDERS CAN REMIND CLIENTS:

- To answer the five Ws: who do you want to tell (persons), why do you want to tell them (reasons/benefits), when and where do you want to tell them (time/place), and how do you want to tell them (method).
- To do a cost benefit analysis and identify potential outcomes (including personal management in the event of secondary disclosure)
- Everyone does not have to know the client's HIV status
 - Doctors, Mental Health Providers, Sex and Drug Partners Need To Know
 - Employers and Co-Workers may not always need to know
 - The longer a person waits to disclose to partners the harder disclosure is going to be
 - Create a standard disclosure plan of action that may include timeline and a setting that helps ensure a safer outcome for the HIV positive individual
- Disclosing is as much about your emotional well-being as it is about your partner's exposure to disease
- In a domestic violence situation, disclosure is not the priority; getting the client out of harm's way is the priority.

WHEN DISCLOSING...

- Be honest
- Be concise, small bites of information are easier to deliver and digest
- Use words the person will understand, avoid jargon and acronyms

- Try not to dwell on the negative
- Let them know who they can talk to about HIV and where they can get support if they need it
- Use the person's experience with or knowledge of HIV as a starting
- Have a reply prepared for intrusive questions regarding personal medical information, such as route of transmission
 - o Your status doesn't give others the right to invade your medical privacy
 - o Offer brochures and HIV hotline numbers for those needing additional information

DISCLOSING TO CHILDREN

- Ask why you want to disclose to children
- Consider the age appropriateness of the information you plan to disclose and the level of information you are offering
- If the child is the client's, identify children's books that can help the child deal with the subject matter and provide the name of another adult (family, friend, etc,) or care provider the child can discuss their feelings with other than the client
- Provide access, if possible, for support groups for other affected and infected children.
- If the person needs free age-specific "scripts" for disclosing to an HIV positive child that the child or the parent and the child both have HIV, please visit:

<http://www.chiva.org.uk/protocols/supportdocs/pdfdocs/talking-with-children.pdf>

PROVIDERS SHOULD KEEP IN MIND THAT...

- Disclosure is a life long process for HIV positive individuals

- There is not always forward movement on disclosure, regression for even those who previously disclosed can occur
- Disclosure is a two-way street. In any sexual negotiation discussions, both partners are responsible for their own risk and need to offer honest disclosure of their HIV status prior to sexual intimacy
- Laws may mandate HIV positive disclosure *and* require legal evidence of disclosure beyond the client's word, discuss strategies for disclosure in ways that offer legal protection
- HIV positive youth may disclose to some but not to all of their friends, partners, etc.
- Clients are more likely to disclose with longer term intimate partners than casual partners
- Disclosure may vary depending on the partner's perceived HIV status, level of risk, use of drugs or alcohol, and sense of personal responsibility to protect the partner
- Even with disclosure, unsafe sex may occur
- Even without disclosure, safer sex may occur
- Clients with low or undetectable viral loads may mistake less infectious to mean zero infectiousness—remind them that even with a lower viral load, HIV can be transmitted to others.
- Listen to your client to partner with them through disclosure, not to direct them.

APPENDIX II

Treatment Adherence and Secondary Prevention

HIV positive youth need information on how to prevent new sexually transmitted infections (STIs) and HIV re-infection to avoid further spread of HIV, but also to prevent acceleration of disease progression or interfere with health regimes. Risk reduction education and planning are part of a comprehensive package needed to comprehensively address youth's secondary HIV prevention needs. Treatment adherence is another core component of secondary HIV prevention. While the goals of primary care are to:

- Determine the stage of HIV disease
- Provide on-going health maintenance
- Monitor immune function and viral load
- Provide client education about HIV and risk reduction
- Provide access to state of the art treatment and to appropriate clinical trials
- Identify and address psycho-social needs

Barriers to treatment adherence must also be addressed as key factors determining positive health outcomes from secondary prevention interventions. For treatment adherence to be successful, providers must address issues clients' fears, beliefs that the medication will fail to help, mistrust of the medical community and social service providers, low self-efficacy, risk-enriched lifestyles, and a lack of social and housing supports.

TREATMENT ADHERENCE GUIDANCE

Treatment adherence is a core part of secondary prevention, but can be difficult to maintain during the adolescent and young adult years. Though prejudices still happen, providers should know better

than to presume that a young person's age pre-determines an unwillingness to adhere to treatment or a lack of capacity to adhere to even the most complex treatment regimens. Still, HIV positive clients do sometimes fail to adhere to treatment goals. Blaming clients for non-adherence will not address the barriers to treatment adherence, but understanding the reasons, values and perspective of youth clients will. The following are recommendations for care clinicians for improving treatment adherence outcomes for youth. Case managers can partner with clinicians, youth and families and review these recommendations:

- Encourage openness about non-adherence, ask open-ended questions.
- Involve the young person as much as possible in regimen planning, drug selection, and dose timing—offer alternatives.
- Identify motivating factors that may help youth maintain in treatment, prompt discussions regarding youth potential concerns about weight and appearance
- Work with youth to process a cost-benefit analysis from their perspective identifying the benefits of treatment adherence
- Make a contract with youth where both sides agree to fulfill certain conditions surrounding treatment adherence
- Provide written instruction in adolescent friendly language about the treatment regimen
- Focus the regimen on the last chaotic time in the adolescent's daily life, usually before school
- For complex regimen, do not assume adherence is the same for each drug (youth may only commit to part of a regimen). Discuss individual drugs. Youth may avoid adherence to some drugs based on side effects or fears regarding specific medications
- Consider text prompts and other memory accessories
- Discuss ways with caregivers to administer regular adherence checks without resorting to nagging or inspiring adolescent rebellion

Treatment adherence is but one practice and educational need for HIV positive youth engaging in secondary prevention. HIV positive youth need explicit secondary prevention education intervention(s) to avoid co-morbidities and further spread of the virus. Youth providers cannot assume youth consumers will receive secondary prevention information through an age appropriate intervention in an adult service provider setting. Interventions offered in adult settings may fail to recognize the cognizant and developmental capacities of adolescence and the unique characteristics of adolescence and young adulthood in their delivery of prevention education information and skills-building. HIV positive youth also fail to receive adequate HIV prevention education information through the public school system, even in systems that offer comprehensive sexuality education, since these programs generally fail to recognize the existence of youth already infected in their target audience and message delivery.

HIV positive youth also may not see the need for accessing and implementing HIV prevention information once they are HIV infected, particularly those youth who sero-sort their intimate partners so as to only engage in sexual activities with partners they already know to be HIV infected. HIV positive youth who sero-sort with positive partners may believe that they are at low to no risk for HIV or any other communicable diseases. However, HIV positive youth need to be concerned not only with further transmitting the virus to HIV negative partners or partners of unknown status, but they also need to be educated about the possibility of acquiring or transmitting a different strain of HIV or acquisition of a co-morbidity such as Hepatitis C (primarily through drug use) or sexually transmitted infections (STIs). While youth may be aware of the health benefits of good nutrition and general health, HIV positive youth may also need to be educated on the role of viral suppression and care maintenance as tools in further preventing communication of their HIV virus to others.

The following is an outline of the issues providers should be prepared to discuss, the co-factor and ancillary concerns that can decrease youth's willingness to engage in secondary HIV prevention activities, and the necessary referrals providers may need on hand, if the specific service required is not available through your agency. It is written with a case manager or other psycho-social support practitioner in mind.

WHAT IS SECONDARY PREVENTION?

HIV prevention interventions targeting those who are infected to:

- Reduce transmission to those uninfected
- Prevent new incidence of other STDs
- Prevent acquisition of stronger or drug-resistant strains of HIV
- To prevent the increased spread and prevalence of drug-resistant HIV
- To prevent rapid disease progression
- To increase the potential longevity and improved quality of life for infected individuals

WHAT ARE THE WAYS PROVIDERS CAN ASSIST HIV POSITIVE PEOPLE IN ACHIEVING SECONDARY PREVENTION GOALS?

Secondary Prevention Basics: Provider Programs can address...

- Lack of knowledge about HIV transmission risks
- Misconceptions about risks of specific sexual and drug use taking practices
- Misconceptions about viral load and transmission of HIV
- How to disclose HIV sero-positive status to a sex partner, family member, or friend
- Importance of using a condom or not exchanging fluids with partners
- Ways to reduce the number of sex or drug partners
- Ways to keep condoms accessible

- Ways to remember to use condoms
- Ways to obtain support (e.g., emotional, financial) from family, friends, and intimate partners;
- Ways to clean/disinfect injection equipment
- Ways to obtain clean needles
- Ways to avoid sharing injection equipment
- How to persuade a sex partner to use a condom and other negotiation skills
- Ways to deal with mild psychological distress stemming from situational circumstances

SECONDARY PREVENTION CORE ELEMENTS

Skills

- Disclosure Skills
- Personal Problem-Solving
- Short- and Long-term Goal Setting
- Emotional Awareness and Regulation (include. Sexual and Substance Use Triggers)
- Assertive Behavior and Communication
- Identification of an Ideal Self
- TB and HEP ABC Awareness and Prevention Efficacy
- Abstinence
- Barrier Method Efficacy

Knowledge

- Treatment Options and Clinical Negotiation
- Education on PEP
- Education on Treatment Adherence and Drug Holiday Consequences
- Identifying and Correcting Risk and Treatment Misconceptions
- STD and Re-infection Risks
- Risk Reducing Sexual Alternatives to Unprotected Intercourse
- Needle Sharing Risks, Elimination and Harm Reduction Methods
- Legal and Policy Protections

Screenings

- Behavioral Risk Screening
- STD Risk Screening
- TB and Hep C Screening
- Screening for Pregnancy
- Clinical Testing (CD4, viral, etc.)

Support

- Exposure to Routine Prevention Messaging
- Group Norming and Support of Risk Reduction KABB
- Support in Poz Identity and Stigma Management

- Advocacy/Community Mobilization
- Drug, Alcohol and/or Sexual Addiction Harm Risk Reduction Support

Individual and Partner Services

- Partner Counseling and Referral Service (Partner Notification)
- Partner Counseling (Sero-Mixed and Concordant Status)
- CRCS
- Mental Health Counseling
- Chemical Dependency Treatment Programs
- Peer Education Programs

If a provider is looking to conduct Centers for Disease Control approved secondary prevention interventions into their HIV care plan for youth there are four currently approved for use. They are:

- Together Learning Choices (formerly Teens Linked to Care)
- Healthy Relationships
- Holistic Health Recovery Program (HIV positive and negative IDUs)
- Comprehensive Risk Counseling Service (CRCS)

Providers may also need to partner with youth to address or identify services that can address life skills, coping strategies, and high risk issues related to the acquisition of co-morbidities and re-infection. High risk co-factors and ancillary youth concerns that providers need to be prepared for include:

- Need for alternate, intensive HIV prevention intervention
- Excessive use of alcohol and drug use
- Tobacco control and smoking cessation issues
- Depression, anger, guilt, fears, etc...
- Isolation, need for social support
- Sexual compulsivity
- Sexual or physical abuse trauma victim and/or DV perpetrator
- Contraceptive counseling/family planning
- Housing or transportation needs
- Nutritional needs
- Financial emergencies
- Child custody, parole, or other legal matters
- Insurance coverage
- Transgender-specific health concerns (drug interaction with hormone therapies/industrial silicon interaction, etc.)

SECONDARY PREVENTION BASICS:WHICH ON HAND REFERRALS ARE NEEDED?

Referrals to:

- Housing
- Transportation
- Health (CD4 count and viral load testing)
- Mental Health
- Substance Abuse
- Primary Care/Treatment
- STD/Hep C Testing
- Social/Life Resources
- Domestic Violence Prevention Services
- Education/Workforce Development

APPENDIX III

Entitlements

Government entitlement programs provide individuals with personal financial benefits (or sometimes special government-provided goods or services) to which an indefinite number of potential beneficiaries have a legally enforceable right whenever they meet eligibility conditions that are specified by the standing law authorizing the program.

People Living With HIV/AIDS (PLWHAs) are eligible for several federally sponsored entitlements from various federal agencies, each with their own systems, rules, regulations, and eligibility requirements. The following is a synthesis of basic information available through each federal website about the core benefits young people transitioning into adulthood may be eligible for, including: Ryan White, Medicare/Medicaid, Food Stamps, Social Security Disability and Supplemental Security Income. Other state and local programs may also offer additional entitlements depending on funding and eligibility requirements.

Providers working with youth should prepare as early as possible to help clients navigate these systems and to familiarize themselves with the websites of these agencies, as most have a plain language Frequently Asked Questions (FAQ) section and Beneficiary portals with dozens of resource tools. Providers should be prepared to walk through these sites and resource tools with young people to ensure comprehension of what can be sometimes be a labyrinth of legalese and public health jargon if a person's strays to denser policy and practitioner sections of these sites.

SOCIAL SECURITY AND SUPPLEMENTAL SECURITY INCOME

The Social Security and Supplemental Security Income disability programs are the largest of several federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration (SSA) and only individuals who have a disability and meet medical criteria may qualify for benefits under either program.

Social Security Disability Insurance pays benefits to individual beneficiaries and certain family dependents of the beneficiary if the individual is "insured," meaning that the beneficiary worked long enough and paid Social Security taxes. Supplemental Security Income pays benefits based on financial need.

When applying for either program, the SSA will collect medical and other information from the applicant and make a decision about whether or not the applicant meets Social Security's definition of disability.

The definition of disability under Social Security is different than other programs. Social Security pays only for total disability. No benefits are payable for partial disability or for short-term disability.

"Disability" under Social Security is based on an applicant's inability to work. Applicants are considered disabled under Social Security rules if:

- You cannot do work that you did before;
- SSA decides that you cannot adjust to other work because of your medical condition(s); and
- Your disability has lasted or is expected to last for at least one year or to result in death.

This is a strict definition of disability. Social Security program rules assume that working families have access to other resources to provide support during periods of short-term disabilities, including workers' compensation, insurance, savings and investments.

Applicants should use the Benefits Eligibility Screening Tool to find out which programs may be able to pay benefits. The Benefits Eligibility screening tool is located at http://connections.govbenefits.gov/ssa_en.portal.

If an application has recently been denied, the Internet Appeal is a starting point to request a review of the SSA's decision about an applicant's eligibility for disability benefits. If your application is denied for medical reasons, you can complete and submit the required Appeal Request and Appeal Disability Report online. The Appeal Request and Appeal Disability Report can be located on the web at <https://secure.ssa.gov/apps6z/iAppeals/ap001.jsp>.

The disability report asks for updated information about an appeal candidate's medical condition and any treatment, tests or doctor visits since the SSA made its decision. For non-medical reasons (e.g., mental health), candidates should contact your local Social Security Office to request the review. To identify a local Social Security Office, visit <https://secure.ssa.gov/apps6z/FOLO/fo001.jsp>. Benefit candidates also may call the SSA at a toll-free number, 1-800-772-1213, to request an appeal. People who are deaf or hard of hearing can call the toll-free TTY number, 1-800-325-0778. For more information or to apply for benefits visit the Social Security website at www.socialsecurity.gov. Beneficiaries can also request a replacement Medicare card through the SS website.

If approved for Social Security, payments cannot begin until a beneficiary has been disabled for at least five full months. Payments usually start on the sixth month of disability. A Social Security approval notice will explain benefits, benefit amounts and the payment start date.

Generally, disability benefits will continue as long as a beneficiary's medical condition has not improved and the beneficiary cannot work. Benefits will not necessarily continue indefinitely. Because of advances in medical science and rehabilitation techniques, many people with disabilities recover from serious accidents and illnesses.

A beneficiary's case will be reviewed at regular intervals to make sure the person is still disabled. Beneficiaries are responsible for telling Social Security if your medical condition improves, if there is any change in your ability to work or if you return to work.

Benefit Payments

Social Security benefits are paid each month. Generally, the day on which a beneficiary receives payments depends on the birth date of the person on whose work record the applicant receives benefits. For example, if you receive benefits as a disabled worker, your benefit will be determined by your birth date. If you receive benefits as a spouse, your benefit payment date will be determined by your spouse's birth date.

COLA

Each January, benefits will increase automatically if the cost of living has gone up. For example, if the cost of living has increased by 2 percent, benefits also will increase by 2 percent. Cost of living adjustments (COLA) will be explained through written notice.

Supplemental Security Income (SSI)

If an applicant has limited income and resources, he or she may be able to get SSI. SSI is a federal program that provides monthly payments to people age 65 or older and to people who are blind or disabled. If you get SSI, you also may be able to get other benefits, such as Medicaid and food stamps.

For more information about SSI, ask for *Supplemental Security Income (SSI)* (Publication No. 05-11000).

Medicare Benefits for Persons with Disability Benefits

After receiving disability benefits for 24 months, a beneficiary will be eligible for Medicare. Social Security beneficiaries will get information about Medicare several months before coverage starts. Those with permanent kidney failure requiring regular dialysis or a transplant, or persons afflicted by amyotrophic lateral sclerosis (Lou Gehrig's disease), may qualify for Medicare almost immediately.

Help for Low-Income Medicare Beneficiaries

If a person receives Medicare and has low income and few resources, the person's state may pay for Medicare premiums and, in some cases, other "out-of-pocket" medical expenses such as deductibles and coinsurance. Only a beneficiary's state can decide if that person qualifies. To determine eligibility, contact your state or local welfare office or Medicaid agency. Also, more information is available from the Centers for Medicare & Medicaid Services. If interested in learning more, ask for *If You Need Help Paying Medicare Costs, There Are Programs That Can Help You Save Money* (CMS Publication No. 10126) by calling the Medicare, toll-free number, 1-800-MEDICARE (1-800-633-4227). If you are deaf or hard of hearing, you may call TTY 1-877-486-2048.

SUPPLEMENTAL NUTRITION ASSISTANCE PROGRAM (FOOD STAMPS)

Previously known as the Federal Food Stamp Program, the Supplemental Nutrition Assistance Program (SNAP) is the federal food and nutrition entitlement. Please note that state programs may

have a different name. Nearly all federal disability recipients are eligible for SNAP, particularly if all members of the household receive SSI or TANF. Generally, a person is considered to be disabled for SNAP purposes if he or she:

- Receives Federal disability or blindness payments under the Social Security Act, including Supplemental Security Income (SSI) or Social Security disability or blindness payments; or
- Receives State disability or blindness payments based on SSI rules; or Receives a disability retirement benefit from a governmental agency because of a disability considered permanent under the Social Security Act; or
- Receives an annuity under the Railroad Retirement Act and is eligible for Medicare or is considered to be disabled based on the SSI rules; or
- Is a veteran who is totally disabled, permanently housebound, or in need of regular aid and attendance;
- or Is a surviving spouse or child of a veteran who is receiving VA benefits and is considered to be permanently disabled.

Persons with disability benefits can obtain a food stamp application and information at any Social Security or SNAP office. To get the telephone number for your state office visit: http://www.fns.usda.gov/fsp/contact_info/hotlines.htm.

For persons not on SSI or TANF, a household income test of both gross and net income is required. To determine income eligibility requirements to receive food stamps for those who are not receiving disability benefits, please visit <http://www.snap-step1.usda.gov/fns/>.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

The Centers for Medicare and Medicaid Services (CMS) is the federal agency responsible for administering Medicare entitlements and the federal aspects of the Medicaid program. As it relates to HIV and AIDS service, CMS has resources that explains for HIV positive individuals the federal eligibility requirements for Medicare and can guide those individuals to state administered Medicaid eligibility requirements. Some HIV positive individuals dually qualify for both Medicare and

Medicaid. CMS can help individuals determine how and whether they can access both programs' services.

One key CMS service that may be critical for Medicare eligible HIV positive individuals is the prescription drug coverage available to anyone with Medicare. Established in January 2006, the prescription drug benefit can assist HIV positive people in paying for their HIV/AIDS medications. All Medicare drug plans cover all antiretroviral medications. Through its website, CMS offers a publication, "Your Guide to Medicare Prescription Drug Coverage," that describes the scope, eligibility requirements, and the steps individuals can take to access of this benefit.

As a state administered entitlement, Medicaid benefits available for HIV positive persons should be accessed by through their local state Medicaid agency website or by visiting their state Medicaid office. The CMS website, <http://www.cms.hhs.gov/>, can provide a general overview of Medicaid Services and the range of health services potentially covered by Medicaid.

RYAN WHITE MODERNIZATION TREATMENT ACT

The Ryan White Treatment Modernization Act of 2006 is the payer of last resort, but one frequently used to resource the care, support and treatment needs of HIV positive individuals and families. While providers are often familiar with part of the act, rarely are they familiar with all of the services Ryan White covers. HIV positive youth may not need to be well versed the act itself, but they should know what entitlements are available to them, should they prove eligible for assistance. The following provides the most current overview of the Modernization Act and the services available within that Act.

What Is The Ryan White Treatment Modernization Act 2006?

The Ryan White Treatment Modernization Act (previously known as the Ryan White CARE Act) is a Federal law that funds services for people living with HIV/AIDS (PLWH) who can not afford to pay for the care they need. Ryan White helps cities, states, and other areas pay for the high costs of HIV/AIDS care including medication. It also pays for care that is not covered by other programs like Medicaid and Medicare.

The Ryan White Treatment Modernization Act 2006 describes eligibility and usage of funds. Most Ryan White money goes towards paying for medical services and support services for people living with HIV/AIDS and their families. The primary goal of Ryan White is to get people who need HIV care receiving services early and provide the support to keep them there and remain healthy.

The majority of Ryan White funds are given to cities and states to address the HIV care needs of PWAs. Many decisions about how to use the funds are made by local planning councils and state planning groups. These planning groups work as partners with the local governments.

The Ryan White Treatment Modernization Act has 5 major parts:

- Part A provides funding to metropolitan areas hardest hit by the HIV epidemic
- Part B provides funding to States. It includes the AIDS Drug Assistance Program (ADAP)
- Part C provides direct funding to community early intervention services
- Part D provides funding to organizations supporting health services for infants, children, youth, and women with HIV disease and their families
- Part F includes Special Programs of National Significance (SPNS) models of care, AIDS Education and Training Centers (AETC) training for health care providers, HIV/AIDS Dental Reimbursement Program, and the Minority AIDS Initiative (MAI) to reduce racial/ethnic disparities in service access and outcomes

PART A: funding goes to cities and metropolitan areas that are hit hardest by the HIV epidemic

Part A of the Ryan White Treatment Modernization Act of 2006 provides emergency assistance to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs) that are most severely affected by the HIV/AIDS epidemic.

To be an eligible EMA, a local area must have reported at least 2,000 AIDS cases in the most recent 5 years and have a population of at least 50,000. In order to be eligible for a TGA, a local area must have reported at least 1,000 - 1,999 new AIDS cases in the most recent five years. When the first

Part A grants were awarded in FY 1991, there were 16 EMAs. Today, 22 EMAs and 34 TGAs receive Ryan White funding.

So who's is responsible for Part A funding?

Part A money goes to the chief elected official (CEO) of the major city or county government in the EMA or TGA. The CEO is the person who is in charge of a major city or county. The CEO is usually the mayor although sometimes it is the county executive, chair of the board of supervisors, or judge. The CEO is legally the grantee, but usually chooses a department such as the health department or other entity to manage the grant. That entity is then referred to as the grantee. The grantee manages the grant by making sure the funds are used correctly and all the rules about using Ryan White Part A funds are followed. The CEO is also responsible for establishing the planning council and appoints its members. The grantee works with the Part A planning council in making decisions about how to use the funds.

Part A funds may be used for HIV primary medical care and other medical related and support services that help people stay in care. A limited amount of Part A funds can be used for planning, managing, and evaluating programs, and for supporting the work of the planning council.

Funding

In FY 2007, \$603,993 million was appropriated for Part A spending. Part A funding to EMAs/TGAs includes formula and supplemental components, as well as Minority AIDS Initiative funds targeted for services to minority populations.

- Formula grants are based on reported living HIV/AIDS cases as of December 31 for the most recent calendar year that data is available.
- Supplemental grants are awarded competitively based on demonstrated need and other criteria.

Services

Part A grantees are required to use 75 percent of the award for core medical services and 25 percent for support services. Core services are limited to: outpatient and ambulatory services; AIDS pharmaceutical assistance; oral health; early intervention services; health insurance premium and cost sharing assistance for low-income individuals; home health care; medical nutrition therapy;

hospice services; home and community-based health services; mental health services; substance abuse outpatient care; and medical case management, including treatment adherence services.

Support services must be linked to medical outcomes and may include: outreach; medical transportation, linguistic services; respite care for person caring for individuals with HIV/AIDS; referrals for health care and other support services; case management; and substance abuse residential services.

PART B: States, including AIDS Drug Assistance Program (ADAP)

Part B of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 provides grants to all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and five U.S. Pacific Territories or Associated Jurisdictions. Part B grants include a base grant, the AIDS Drug Assistance Program (ADAP) award, ADAP Supplemental grants and grants to States for Emerging Communities—those reporting between 500 and 999 cumulative reported AIDS cases over the most recent 5 years. All funding is distributed via formula and other criteria.

Like Part A funds, Part B funds can be used for core medical and support services. A major priority is providing medications for people with HIV and AIDS. The Ryan White legislation gives States flexibility to deliver these services under five different programs:

- The AIDS Drug Assistance Program which provides medication to treat HIV disease
- Health insurance coverage
- Home and community-based care
- Services provided through consortia—a consortia is a group of providers and community members that plan and deliver care, and
- Direct services provided or contracted by the State.

One of the key differences between Part A and B is that States awarded Part B funds decide how to spend the funds. There is no planning council requirement for Part B, however many States get input from Part B planning groups. States are required to conduct a needs assessment to determine

the needs of persons living with HIV and use it to set priorities and allocate resources to meet needs. States must also write a comprehensive plan, which is a guide on how to meet those needs.

Funding

Like Part A, Part B funds may be used to fund 75% core medical services which include: outpatient and ambulatory health services, ADAP, AIDS pharmaceutical assistance, oral health care, early intervention services, health insurance premium and cost sharing assistance, home health care, medical nutrition therapy, hospice care, community-based health services, substance abuse outpatient care, medical case management, include treatment adherence services.

The remaining 25% must fund support services that are needed for individuals with HIV/AIDS to achieve their medical outcomes (such as respite care for persons caring for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referrals for health care and support services.

In fiscal year 2007, a total of \$1.195 billion was allocated to Part B programs, of which \$789,546 million was given or ADAP.

- Part B grants are awarded to States and Territories using a formula that is based on living cases of HIV/AIDS reported. Also States with more than 1% of total AIDS cases reported in the United States during the previous 2 years must provide matching funds with their own resources using a formula outlined in the legislation.
- Additional Part B funds are "earmarked" for ADAP, which primarily provide medications. Fundable services also include treatment adherence and support as well as health insurance coverage with prescription drug benefits. 5% of the ADAP earmark is reserved for grants to States and Territories that have a severe need for medication assistance.
- Part B provides \$5.0 million in supplemental grants to States for Emerging Communities-cities with between 500 and 999 reported AIDS cases in the most recent 5 years.

Providers

Part B providers may include public or nonprofit entities. For-profit entities are eligible only if they are the sole available providers of quality HIV care in the area.

Most States provide some services directly, but others work through subcontracts with Part B HIV Care Consortia. A consortium is an association of public and nonprofit health care and support service providers and community-based organizations that plans, develops, and delivers services for people living with HIV disease. Services provided through a consortium are considered support services.

AIDS DRUG ASSISTANCE PROGRAM (ADAP)

The majority Part B funding and about one third of Ryan White funding is earmarked by Congress for the AIDS Drug Assistance Program (ADAP). Funding for ADAP is given to States based on that State's proportion of the nation's living AIDS cases.

There are ADAPs in 57 areas including all 50 states, Puerto Rico, the District of Columbia, the Marshall Islands, Guam, the U.S. Virgin Islands, American Samoa, and the Northern Mariana Islands. The purpose of ADAP is to provide prescription drugs to eligible persons living with HIV. The drugs must be approved by the Food and Drug Administration. ADAPs can also use funds to pay to continue an eligible individual's private health insurance, if it has prescription drug coverage, or to fund treatment adherence programs for clients.

For an individual to receive ADAP assistance they must be medically diagnosed with HIV. They must qualify as "low income," as defined by the state. States receiving ADAP funding have the flexibility in designing their program, setting income and medical eligibility requirements and developing drug formularies. A drug formulary is a listing of all drugs funded by the state's ADAP.

Eligibility

Each State and Territory establishes its own eligibility criteria. However, all States/Territories are required to implement an ADAP recertification process every six months to ensure only eligible clients are served. All States/Territories require that program participants document their HIV status. Clients must be low income, and under or uninsured. Also all ADAPs require that clients be residents in their state, and most require proof of residency.

PART C: Community Early Intervention Services

Part C of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 provides grants directly to community-based organizations such as ambulatory medical clinics to support outpatient HIV early

intervention services and ambulatory care. Awards are given to the following public, private and nonprofit organizations:

- Community Health Centers,
- Migrant Health Centers, and
- Health Care for the Homeless sites funded under Section 330 of the Public Health Service (PHS) Act
- Family planning grantees (other than States) funded under Section 1001 of the PHS Act
- Comprehensive Hemophilia Diagnostic and Treatment Centers
- City and county health departments
- Academic medical centers
- Federally qualified health centers (FQHCs)
- Current public or private not-for-profit providers of comprehensive primary care for populations at risk for HIV
- Faith-based and community-based organizations.

The funds are used to reach people early in their HIV disease and to link them to care. These are called Early Intervention Services (EIS). EIS include HIV counseling and testing, medical care, support services, and referrals to services. A small amount of funds can be used for capacity building and planning at awarded organizations.

All Ryan White programs can provide EIS. Part C is unique because competitive awards go directly to community based organizations, often community health centers. Part C programs operate in many areas, but the priority is to fund rural areas and locations that lack HIV-related health services.

Part C: Early Intervention Services

Part C Early Intervention Services of the [Ryan White HIV/AIDS Treatment Modernization Act of 2006](#) funds comprehensive primary health care in an outpatient setting for people living with HIV disease.

Services

The Part C Program divides allowable costs among five Part C Cost Categories. These categories are Early Intervention Services Costs, Core Medical Services Costs, Support Services Costs, Quality Management Costs, and Administrative Costs.

Early Intervention Services Costs are those costs associated with the direct provision of medical care and make up at least 50 percent of a grantee budget. Services include:

- Primary care providers
- Lab, x-ray, and other diagnostic tests
- Medical/dental equipment and supplies
- Medical Case Management
- Electronic Medical Records
- Patient education, in conjunction with medical care
- Transportation for clinical care provider staff to provide care
- Other clinical and diagnostic services regarding HIV/AIDS and periodic medical evaluations of individuals with HIV/AIDS

Core Medical Services Costs include those listed above plus the following:

- HIV Counseling

- The following core medical services have historically been paid by Parts A or B (Titles I or II) but not Part C (Title III), and should only be provided by Part C with justification.
- AIDS Drug Assistance Program
- Health Insurance Premium and cost sharing assistance for low income individuals
- Home health care
- Hospice Services
- Home and community-based health services as defined under Part B

Clinical Quality Management Costs are those costs required to maintain a clinical quality management program. With a HAB expectation that no more than 5 percent of the grant be spent on Clinical Quality Management, examples include:

- Continuous Quality Improvement (CQI) activities
- Clinical Quality management coordination
- Data collection for clinical quality management purposes
- Consumer involvement to improve services
- Staff training/technical assistance (including travel and registration) to improve services- this includes the annual clinical update and the biennial All Grantee Meeting, as well as local travel to meetings not directly related to patient care

Support Services Costs are those costs for services that are needed for individuals with HIV/AIDS to achieve their medical outcomes. Support Services Costs include:

- Patient transportation to medical appointments

- Staff travel to provide support services
- Outreach to identify people with HIV, or at-risk of contracting HIV, to educate them about the benefits of early intervention and link them into primary care
- Translation services, including interpretation services for deaf persons
- Patient education materials for general use
- Participation in Statewide Coordinated Statement of Need process
- Patient advocates to maintain access to care
- Respite Care (historically paid by Parts A or B (Titles I or II) but not Part C (Title III), and should only be provided by Part C with justification)

Administrative Costs are those not directly associated with service provision. By law, no more than 10 percent of a Federal Part C EIS budget can be allocated to administrative costs. Examples of administrative costs include:

- Indirect costs, which are allowed only if the applicant has a negotiated indirect cost rate approved by a recognized Federal agency. Indirect costs are those costs incurred by the organization that are not readily identifiable with a particular project or program, but are considered necessary to the operation of the organization and performance of its programs. All indirect costs are considered administrative for the Part C EIS program and therefore are subject to the 10 percent limitation on administrative expense.
- Rent, utilities, and other facility support costs
- Personnel costs and fringe benefits of staff members responsible for the management of the project (such as the Project Director and program coordinator), non-CQI program evaluation, non-CQI data collection/reporting, supervision, and other administrative, fiscal, or clerical duties

- Telecommunications, including telephone, fax, pager and internet access
- Postage
- Liability insurance
- Office supplies
- Audits
- Payroll/Accounting services
- Computer hardware/software not directly related to patient care
- Program evaluation, including data collection for evaluation

Part C: Planning Grant Program

Part C Planning Grant Program of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 funds eligible entities in their efforts to plan for the provision of high-quality comprehensive HIV primary health care services in rural or urban underserved areas and communities of color. Planning grant funds are intended for a period of 1 year. Planning grants support the planning process and do not fund any service delivery or patient care.

Eligibility

Eligible applicants must be public or private nonprofit entities that are or intend to become a comprehensive HIV primary care provider. Current Ryan White Programs Part C EIS and Part D Program grant recipients are eligible only if they are proposing to open a new program. Faith-based and community-based organizations are eligible to apply for these funds.

Fundable Activities

Part C planning grants can include the following activities:

- Identifying key stakeholders and engaging and coordinating potential partners in the planning process
- Gathering a formal advisory group to plan for the establishment of services
- Conducting an in-depth review of the nature and extent of the need for HIV primary care services in the community (including a local epidemiological profile, an evaluation of the community's service provider capacity, and a profile of the target population)
- Defining the components of care and forming essential programmatic linkages with related providers in the community
- Researching funding sources and applying for operational grants.

Part C: Capacity Development Grant Program

Part C Capacity Development Grant Program of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 are designed to assist public and nonprofit entities in their efforts to strengthen their organizational infrastructure and to enhance their capacity to develop, enhance, or expand access to high quality HIV primary health care services for people living with HIV or who are at risk of infection in underserved or rural communities and communities of color.

Activities supported by this grant funding are not intended for long-term activities. Instead, the activities should be of a short-term nature and should be completed by the end of the one year project period.

For the purposes of this grant program, capacity development is defined as activities that promote organizational infrastructure development and that will lead to the delivery or improvement of HIV primary care services.

Eligibility

Eligible applicants must be public or private nonprofit entities that are or intend to become comprehensive HIV primary care providers. Current Ryan White Programs service providers are

eligible to apply for funding. Faith-based and community-based organizations are eligible to apply for these funds.

Fundable Activities

Part C capacity development activities fall into five infrastructure development categories: Management Systems; Service Delivery Systems; Evaluation Systems; Cultural Competency; and Self Management.

Fundable activities under these categories include:

- Identifying, establishing and strengthening clinical, administrative, managerial, and management information system (MIS) structures.
- Developing a financial management unit of the organization that is capable of managing multiple sources of funding for HIV primary care services;
- Developing and implementing a clinical continuous quality improvement (CQI) program
- Gathering necessary documents and applying for Medicaid certification and if applicable, appropriate state clinic licensure.
- Increasing the capability of your organization to oversee its HIV service provision, including development of an organizational strategic plan for HIV care, education of Board members regarding the HIV program, and staff training and development regarding HIV care
- Purchasing clinical supplies and equipment for the purpose of developing, enhancing, or expanding HIV primary care services (i.e., purchase of dental chairs and equipment to begin an HIV dental clinic; modification of a ventilation system to accommodate TB care, etc.);
- Developing an organizational strategic plan to address managed care changes or changes in the HIV epidemic in your community;
- Developing a cultural competency training program aimed at staff or other HIV provider partners.

- Increasing the capability of your organization to implement and/or manage consumer involvement.
- Developing a Patient Self Management support program that emphasizes the patient's role in the management of their health.

PART D: Services for infants, children, youth, and women with HIV disease and their families

Part D of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 provides funds for family centered care involving outpatient or ambulatory care for women, infants, children, and youth with HIV/AIDS. The main focus of Part D is to identify HIV positive pregnant women and ensure that they have access to prenatal care to prevent mother-to-child transmission of the virus. Grants are awarded competitively to public and private nonprofit organizations to provide primary and specialty care such as:

- Substance abuse counseling and treatment
- Mental health services
- Transportation
- Child care
- Housing assistance
- Care coordination
- Access to clinical trials and clinical research
- Support services
- Logistical support and coordination of services

Part D grantees are expected to provide care, treatment, and support services or create a network of medical and social service providers, who collaborate to supply services.

PART F

Part F of the Ryan White Treatment Modernization Act of 2006 includes three competitive grants:

- Special Programs of National Significance (SPNS) models of care
- AIDS Education and Training Centers (AETC) training for health care providers
- HIV/AIDS Dental Reimbursement Program

Special Projects of National Significance

The Special Projects of National Significance Program (SPNS) is an integral link to all Ryan White HIV/AIDS programs. The SPNS Program (SPNS) supports the development and replication of innovative models in HIV/AIDS care and service delivery to underserved populations diagnosed with HIV infection. The SPNS Program provides the mechanisms to:

- Quickly respond to emerging needs of individuals receiving assistance under this Part F
- Fund special programs to develop a standard electronic client information data system to improve the ability of grantees under Part F to report client-level data
- To advance knowledge and skills in the delivery of health and support services to people with HIV who are underserved
- Support and assess the effectiveness of new innovative programs
- To fund innovative models of care and to support the development of effective delivery systems of HIV care and services
- Promote the sharing and replication of effective models of care

SPNS grantees include the following:

- Hospitals

- Academic Institutions
- Community Health Centers
- Local or State Health Departments
- Community Based Organizations
- Evaluation Centers

SPNS Initiatives

Current SPNS Initiatives include:

- Prevention with HIV-infected persons seen in primary care settings
- Evaluation of innovative methods for integrating substance abuse treatment in HIV primary care
- Development of outreach, care, and prevention strategies to engage HIV-positive young men who have sex with men of color
- Developing innovative models of care to provide oral health care to HIV-positive, underserved populations
- Enhancement and evaluation of existing health information electronic network systems for PLWHA in underserved communities
- Enhancement of linkages to HIV primary care in jail settings
- Capacity-building to develop standard electronic client information data systems

AIDS Education and Training Centers

The AIDS Education and Training Centers (AETCs) Program of the Ryan White Treatment Modernization Act of 2006 is the clinical training component of the Act. It funds a network of 11 regional and national centers that train health care providers to treat persons with HIV/AIDS.

AETCs seek to improve health outcomes of people living with HIV/AIDS through training on clinical management of HIV disease in such areas as use of antiretroviral therapies and prevention of HIV transmission. During the 2005-2006 grant year, more than 118,760 participants attended AETC training events. The program targets providers who treat minority, underserved, and vulnerable populations in communities most affected by the HIV epidemic.

HIV/AIDS Dental Reimbursement Program

The Ryan White HIV/AIDS Dental Reimbursement Program of the Ryan White Treatment Modernization Act of 2006 was created to address difficulties in access to dental care for persons living with HIV/AIDS. The program provides funding for dental schools, postdoctoral dental programs and dental hygiene programs for the services they provide to individuals without dental insurance and living with HIV/AIDS.

HOUSING OPPORTUNITIES FOR PEOPLE WITH AIDS (HOPWA)

The United States Department of Housing and Urban Development (HUD) is the Federal agency created in 1965 responsible for increasing homeownership, support community development and increase access to affordable housing free from discrimination. Located in Washington, DC HUD is comprised of 16 Program areas which include fair housing, healthcare facility loans, public housing and single family housing Programs.

HUD's Office of HIV/AIDS Housing manages the Housing Opportunities for People with AIDS (HOPWA) Program in collaboration with 44 state and area Community Planning and Development offices in providing guidance and Program oversight. The Office works with other HUD offices to ensure that all HUD Programs and initiatives are responsive to the special needs of people with HIV/AIDS. One of the primary functions of the Office is to administer the Housing Opportunities for Persons with HIV/AIDS Program.

WHAT IS HOPWA?

To address housing needs for low-income persons who are living with HIV/AIDS and their families, the U.S. Department of Housing and Urban Development (HUD) manages the Housing Opportunities for Persons with AIDS (HOPWA) Program. The HOPWA Program is the only Federal Program dedicated to address the housing needs of persons living with HIV/AIDS and their families. Funds are distributed to states and cities based on the number of AIDS cases and made available as part of the area's plan to address the housing needs in that geographic area. In addition, some special housing projects are selected in national competitions to serve as service delivery models or operate in non-formula areas. Grantees partner with nonprofit organizations and housing agencies to provide housing and support to beneficiaries.

PURPOSE OF HOPWA

- The HOPWA Program is responsible for increasing the availability of decent, safe and affordable housing for low-income people living with HIV/AIDS (PLWH).
- The HOPWA Program provides state and local governments with resources and incentives to create long-term strategies for developing a range of housing assistance and supportive services for low-income persons living with HIV/AIDS and their families.
- The HOPWA Program reduces the risk of homelessness.
- The HOPWA Program seeks to improve access to health care and supportive services.

HOPWA Facts

- The HOPWA Program can address a wide range of housing needs.
- The HOPWA Program is one of several solutions for housing someone with HIV disease.
- People living with HIV are considered by HUD to be persons with special needs.
- HOPWA is not a homeless program.
- The HOPWA Program is designed to work with existing housing resources.

- The HOPWA Program helps persons living with HIV/AIDS overcome key barriers to stable housing, affordability and discrimination.

WHO IS ELIGIBLE FOR HOPWA PROGRAMS?

- Persons who are documented to have HIV or AIDS are eligible for HOPWA Programs.
- Persons or households with incomes at or below 80% of the Area Median Income are eligible for HOPWA Programs. The HUD Area Median Income varies from state to state. They can be found at the following web address:

http://www.huduser.org/datasets/il/il2008/select_Geography.odt

What HOPWA services are funded?

- Housing information services which include housing counseling, housing advocacy, information and referral services, and fair housing information, housing search and assistance.
- Resource identification to develop housing assistance resources, outreach and relationship building with landlords, costs involved in creating brochures, web resources and time to locate and identify affordable housing vacancies.
- Acquisition, rehabilitation, conversion, lease and repair of facilities to provide housing and service; requires a 10 year commitment, independent or shared residences; and must meet ADA standards.
- New construction for Single Room Occupancy (SRO) and community residences.
- Project or tenant-based rental assistance, including shared housing arrangements, transitional, and permanent housing.
- Short-term rent, mortgage and utility assistance to prevent homelessness.
- Supportive services, including:

- Health
- Mental Health
- Case management
- Housing placement and advocacy
- Drug and alcohol abuse treatment
- Day care-adult and child
- Personal assistance
- Nutritional services
- Intensive care when required
- Entitlement assistance
- Language translation
- Transportation

HOPWA subgrantees can also be reimbursed for the following:

- **Operating costs for housing which include:**

- **Maintenance and Security**

- **Insurance and Utilities**

- **Furnishings and Equipment**

- **Supplies**

- **Master Leasing**

- **Other incidental expenses**

- **Technical Assistance to include:**

- **Development of comprehensive community-based housing strategies through needs assessment and planning.**

- **Community outreach and education.**

- **Establish and/or operate community residences.**

- **Ensure sound management of HOPWA Program and build sponsor capacity.**

APPENDIX IV Legal Protections for People Living With AIDS

What are the key workplace laws and protections for PLWA/H?

- American With Disabilities Act of 1990 (ADA)
- Occupational Safety and Health Administration (OSHA)
- Family Medical Leave Act of 1993 (FMLA)
- Health Insurance Portability and Accountability Act of 1996 (HIPAA)
- Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA)

ADA

To be protected under the ADA, an individual must have a physical or mental impairment that substantially limits one or more major life activities, must have a record of such an impairment, or be regarded as having such an impairment. The ADA also permits differing treatment in cases where the individual seeking protection is not considered to be otherwise qualified, or because the individual poses a "direct threat" to himself or herself or others that cannot be eliminated through a reasonable accommodation.

To apply the ADA to everyday employment situations, employers must remember four key points:

- The definition of disability
- The importance of knowing the essential functions of jobs

- The concept of reasonable accommodation
- Preserving confidentiality of medical information and limiting medical inquiries within the boundaries of the law

An individual with a disability is a person who:

- Has a physical or mental impairment that substantially limits one or more major life activities
- Has a record of such an impairment
- Is regarded as having such an impairment
- A *qualified* employee or applicant with a disability is an individual who, with or without reasonable accommodation, can perform the essential functions of the job in question. As more effective drug therapies are extending the lives of HIV-positive people—and improving their quality of life—more workers are returning to the workforce and staying productive. Lawsuits filed by HIV-infected workers continue under the ADA. Most of these lawsuits are preventable through training and education.

Reasonable accommodation may include, but is not limited to:

- Making existing facilities used by employees readily accessible to and usable by persons with disabilities
- Job restructuring, modifying work schedules, reassignment to a vacant position
- Acquiring or modifying equipment or devices, adjusting or modifying examinations, training materials, or policies, and providing qualified readers or interpreters

OSHA

The Occupational Safety and Health Administration released its blood borne pathogens standards intended to protect millions of workers across the nation from workplace exposure to HIV and hepatitis. These standards cover employees exposed to blood and other infectious materials,

including but not limited to employees in hospitals, healthcare facilities, nursing homes, and research laboratories.

OSHA says the rules will protect approximately 5.6 million employees in hospitals, doctors' offices, dentists' offices, nursing homes, funeral homes, linen services, medical equipment-repair companies, correctional facilities, emergency-response agencies, and law enforcement agencies. OSHA projects that the new restrictions will prevent 200 deaths and 9,200 blood borne infections annually.

Employers have certain responsibilities under OSHA, including:

- Providing a workplace free from serious recognized hazards and complying with standards, rules, and regulations issued under the OSHA Act
- Examining workplace conditions to make sure they conform to applicable OSHA standards
- Making sure employees have and use safe tools and equipment and properly maintain this equipment
- Establishing or updating operating procedures and communicating them so that employees follow safety and health requirements
- Not discriminating against employees who exercise their rights under the Act

The standard requires employers to:

- develop a written exposure control plan
- establish a Hepatitis B vaccination program
- provide employees with hazard information and training
- maintain certain medical records surrounding exposure incidents

- implement certain work practice controls, such as protective clothing and puncture-proof receptacles for tainted needles and other medical wastes.

FMLA

- FMLA applies to private sector employers with 50 or more employees within 75 miles of the work site. Eligible employees may take leave for serious health conditions or to provide care for an immediate family member with a serious health condition—including HIV/AIDS. Eligible employees are entitled to a total of 12 weeks of job-protected, unpaid leave during any 12-month period.
- During this leave, an eligible employee is entitled to continued group health plan coverage as if the employee had continued to work
- Upon return from leave, the law generally requires that employees be restored to the same or an equivalent position with equivalent pay, benefits, and working conditions.
- In order for individuals with HIV or AIDS to invoke FMLA protection, the disclosure of medical information to the employer may be required. Employers are not required to provide unpaid medical leave under FMLA if they are not informed that a disability or serious health condition exists.
- If an employee makes an employer aware of his or her AIDS or HIV infection, laws such as the ADA require that information to be held in strict confidence.
- Unpaid leaves of absence in addition to leave under the FMLA (or for employees covered by the ADA but not necessarily eligible under FMLA) may also be required as a "reasonable accommodation" under the ADA.

HIPAA

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) attempts to address some of the barriers to healthcare coverage and related job mobility impediments facing people with HIV as well as other vulnerable populations.

HIPAA has three main goals:

- Provides persons with group coverage new protections from discriminatory treatment
- Enables small groups (such as businesses with a small number of employees) to obtain and keep health insurance coverage more easily
- Gives persons losing/leaving group coverage new options for obtaining individual coverage

This law provides several protections important to PLWA/H:

- Limits (but does not wholly eliminate) the use of pre-existing condition exclusions
- Prohibits group health plans from discriminating by denying you coverage or charging additional fees for coverage based on an employee's family member's past or present poor health
- Guarantees certain small employers, and certain individuals who lose job-related coverage, the right to purchase individual health insurance
- Guarantees, in most cases, that employers or individuals who purchase health insurance can renew the coverage regardless of any health conditions of individuals covered under the insurance policy.
- Limits (but does not wholly eliminate) the use of pre-existing condition exclusions
- Prohibits group health plans from discriminating by denying you coverage or charging additional fees for coverage based on an employee's family member's past or present poor health
- Guarantees certain small employers, and certain individuals who lose job-related coverage, the right to purchase individual health insurance

- Guarantees, in most cases, that employers or individuals who purchase health insurance can renew the coverage regardless of any health conditions of individuals covered under the insurance policy

COBRA

The Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) allows employees to continue their health insurance coverage at their own expense for a period of time after their employment ends. For most employees ceasing work for health reasons, the period of time to which benefits may be extended ranges from 18 to 36 months.

If an employee is entitled to COBRA benefits, the employer must give the employee notice of his/her right to continue benefits provided by the plan. The employee must reply within 60 days to accept coverage or forfeit his/her right to continued coverage. Life insurance is not a benefit that must be offered to individuals for purposes of health continuation coverage.

Qualifying events determine how long COBRA coverage will be extended, such as:

- Termination of employment—18 months of coverage
- Disability—18 to 29 months of coverage (coinciding with the Medicare waiting period)
- Reduction of work hours with loss of benefits—18 months of coverage
- Death of covered employee—coverage can be continued indefinitely for an eligible spouse, or until age 23 or marriage for dependents
- Divorce or legal separation from covered employee—36 months of coverage

Medical benefits provided under the terms of the plan and available to COBRA beneficiaries may include:

- Inpatient and outpatient hospital care
- Physician care

- Surgery and other major medical benefits
- Prescription drugs
- Any other medical benefits, such as dental and vision care

Glossary

ADAP (AIDS Drug Assistance Program)

Administered by States and authorized under Part B of the Ryan White Treatment Modernization Act. Provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid. ADAP funds may also be used to purchase insurance for uninsured Ryan White HIV/AIDS Program clients as long as the insurance costs do not exceed the cost of drugs through ADAP and the drugs available through the insurance program at least match those offered through ADAP.

Adolescence

Is the transitional stage of growth and development between the dependency of childhood and the independence of adulthood. It is characterized by development of greater social autonomy, differential personal identity, wider social and personal relationships, growing biological and sexual maturity and increasing cognitive knowledge and competence. Variations exist as to which ages are considered part of adolescence, though the age range in the U.S. is typically 13 to 24.

Administrative or Fiscal Agent

Entity that functions to assist the grantee, consortium, or other planning body in carrying out administrative activities (e.g., disbursing program funds, developing reimbursement and accounting systems, developing Requests for Proposals [RFPs], monitoring contracts).

AETC (see Part F)

AIDS (Acquired Immunodeficiency Syndrome)

A disease caused by the human immunodeficiency virus.

Antiretroviral

A substance that fights against a retrovirus, such as HIV. (See Retrovirus)

ASO (AIDS service organization)

An organization that provides primary medical care and/or support services to populations infected with and affected by HIV disease.

Capacity

Core competencies that substantially contribute to an organization's ability to deliver effective HIV/AIDS primary medical care and health-related support services. Capacity development activities should increase access to the HIV/AIDS service system and reduce disparities in care among underserved PLWH in the EMA.

CARE Act (Ryan White Comprehensive AIDS Resources Emergency Act)

Federal legislation created to address the unmet health care and service needs of people living with HIV Disease (PLWH) disease and their families. It was enacted in 1990 and reauthorized in 1996 and 2000. Reauthorized in 2006 as the Ryan White Treatment Modernization Act.

CBO (community-based organization)

An organization that provides services to locally defined populations, which may or may not include populations infected with or affected by HIV disease.

CDC (Centers for Disease Control and Prevention)

Federal agency within HHS that administers disease prevention programs including HIV/AIDS prevention.

CD4 or CD4+ Cells

Also known as "helper" T-cells, these cells are responsible for coordinating much of the immune response. HIV's preferred targets are cells that have a docking molecule called "cluster designation 4" (CD4) on their surfaces. Cells with this molecule are known as CD4-positive (CD4+) cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and decreasing CD4 levels appear to be the best indicator for developing opportunistic infections.

CD4 Cell Count

The number of T-helper lymphocytes per cubic millimeter of blood. The CD4 count is a good predictor of immunity. As CD4 cell count declines, the risk of developing opportunistic infections increases. The normal adult range for CD4 cell counts is 500 to 1500 per cubic millimeter of blood. (The normal range for infants is considerably higher and slowly declines to adult values by age 6 years.) CD4 counts should be rechecked at least every 6 to 12 months if CD4 counts are greater than 500/mm³. If the count is lower, testing every 3 months is advised. (In children with HIV infection, CD4 values should be checked every 3 months.) A CD4 count of 200 or less is an AIDS-defining condition.

Chief Elected Official (CEO)

The official recipient of Part A or Part B Ryan White HIV/AIDS Program funds. For Part A, this is usually a city mayor, county executive, or chair of the county board of supervisors. For Part B, this is usually the governor. The CEO is ultimately responsible for administering all aspects of their title's CARE Act funds and ensuring that all legal requirements are met.

CMS (Centers for Medicare and Medicaid Services)

Federal agency within HHS that administers the Medicaid, Medicare, State Child Health Insurance Program (SCHIP), and the Health Insurance Portability and Accountability Act (HIPAA).

Community Forum or Public Meeting

A small-group method of collecting information from community members in which a community meeting is used to provide a directed but highly interactive discussion. Similar to but less formal than a focus group, it usually includes a larger group; participants are often self-selected (i.e., not randomly selected to attend).

Comprehensive Planning

The process of determining the organization and delivery of HIV services. This strategy is used by planning bodies to improve decision-making about services and maintain a continuum of care for PLWH.

Community Health Centers

Federally-funded by HRSA's Bureau of Primary Health Care, centers provide family-oriented primary and preventive health care services for people living in rural and urban medically underserved communities.

Consortium/HIV Care Consortium

A regional or statewide planning entity established by many State grantees under Part B of the Ryan White HIV/AIDS Program to plan and sometimes administer Part B services. An association of health care and support service agencies serving PLWHA under Part B.

Continuum of Care

An approach that helps communities plan for and provide a full range of emergency and long-term service resources to address the various needs of PLWHA.

Cultural Competence

The knowledge, understanding, and skills to work effectively with individuals from differing cultural backgrounds.

DCBP (Division of Community Based Programs)

The division within HRSA's HIV/AIDS Bureau that is responsible for administering Part C, Part D, and the HIV/AIDS Dental Reimbursement Program.

DSS (Division of Service Systems)

The division within HRSA's HIV/AIDS Bureau that administers Part A and Part B of the Ryan White HIV/AIDS Program.

DTTA (Division of Training and Technical Assistance)

The division within HRSA's HIV/AIDS Bureau that administers the AIDS Education and Training Centers (Part F) and technical assistance and training activities of the HIV/AIDS Bureau.

Early Intervention Services (EIS)

Activities designed to identify individuals who are HIV-positive and get them into care as quickly as possible. As funded through Parts A and B of the Ryan White HIV/AIDS Program, includes outreach, counseling and testing, information and referral services. Under Part C Ryan White HIV/AIDS Program, also includes comprehensive primary medical care for individuals living with HIV/AIDS.

Eligible Metropolitan Area (EMA)

Geographic areas highly-impacted by HIV/AIDS that are eligible to receive Ryan White HIV/AIDS Program Part A funds.

Epidemic

A disease that occurs clearly in excess of normal expectation and spreads rapidly through a demographic segment of the human population. Epidemic diseases can be spread from person to person or from a contaminated source such as food or water.

Epidemiology

The branch of medical science that studies the incidence, distribution, and control of disease in a population.

Family Centered Care:

A model in which systems of care under Ryan White Part D are designed to address the needs of PLWHA and affected family members as a unit, providing or arranging for a full range of services. Family structures may range from the traditional, biological family unit to non-traditional family units with partners, significant others, and unrelated caregivers.

Grantee

The recipient of Ryan White HIV/AIDS Program funds responsible for administering the award.

Health Insurance Continuity Program (HICP)

A program primarily under Part B of the Ryan White HIV/AIDS Program that makes premium payments, co-payments, deductibles, and/or risk pool payments on behalf of a client to purchase/maintain health insurance coverage.

HIV/AIDS Bureau (HAB)

The bureau within the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) that is responsible for administering the Ryan White Treatment Modernization Act.

HIV/AIDS Dental Reimbursement Program

The program within the HRSA HIV/AIDS Bureau's Division of Community Based Programs that assists with uncompensated costs incurred in providing oral health treatment to PLWHA.

HIV Disease

Any signs, symptoms, or other adverse health effects due to the human immunodeficiency virus.

Home and Community Based Care

A category of eligible services that States may fund under Part B of the Ryan White HIV/AIDS Program.

HRSA (Health Resources and Services Administration)

The agency of the U.S. Department of Health and Human Services that administers various primary care programs for the medically underserved, including the Ryan White HIV/AIDS Program.

IDU

Injection Drug User

Lead Agency

The agency within a Part B consortium that is responsible for contract administration; also called a fiscal agent (an incorporated consortium sometimes serves as the lead agency)

MAI (Minority AIDS Initiative)

A national HHS initiative that provides special resources to reduce the spread of HIV/AIDS and improve health outcomes for people living with HIV disease within communities of color. Enacted to address the disproportionate impact of the disease in such communities.

Formerly referred to as the Congressional Black Caucus Initiative because of that body's leadership in its development.

Needs Assessment

A process of collecting information about the needs of PLWHA (both those receiving care and those not in care), identifying current resources (Ryan White HIV/AIDS Program and other) available to meet those needs, and determining what gaps in care exist.

Part A

The part of the Ryan White HIV/AIDS Program that provides emergency assistance to localities (EMAs) disproportionately affected by the HIV/AIDS epidemic.

Part B

The part of the Ryan White HIV/AIDS Program that provides funds to States and territories for primary health care (including HIV treatments through the AIDS Drug Assistance Program, ADAP) and support services that enhance access to care to PLWHA and their families.

Part C

The part of the Ryan White HIV/AIDS Program that supports outpatient primary medical care and early intervention services to PLWHA through grants to public and private non-profit organizations. Part C also funds capacity development and planning grants to prepare programs to provide EIS services.

Part D

The part of the Ryan White HIV/AIDS Program that supports coordinated services and access to research for children, youth, and women with HIV disease and their families.

Part F (AETC) (AIDS Education and Training Center)

Regional centers providing education and training for primary care professionals and other AIDS-related personnel. Part F (AETC)s are authorized under Part F of the Ryan White HIV/AIDS Program and administered by the HRSA HIV/AIDS Bureau's Division of Training and Technical Assistance (DTTA).

Part F (SPNS) (Special Projects of National Significance)

A health services demonstration, research, and evaluation program funded under Part F of the Ryan White HIV/AIDS Program to identify innovative models of HIV care. Part F (SPNS) projects are awarded competitively.

Planning Council

A planning body appointed or established by the Chief Elected Official of an EMA whose basic function is to assess needs, establish a plan for the delivery of HIV care in the EMA, and establish priorities for the use of Ryan White HIV/AIDS Program Part A funds.

Planning Process

Steps taken and methods used to collect information, analyze and interpret it, set priorities, and prepare a plan for rational decision making.

PLWHA

(People Living with HIV/AIDS)

Priority Setting

The process used to establish priorities among service categories, to ensure consistency with locally identified needs, and to address how best to meet each priority.

Quality

The degree to which a health or social service meets or exceeds established professional standards and user expectations.

QA (Quality Assurance)

The process of identifying problems in service delivery, designing activities to overcome these problems, and following up to ensure that no new problems have developed and that corrective actions have been effective. The emphasis is on meeting minimum standards of care.

Representative

Term used to indicate that a sample is similar to the population from which it was drawn, and therefore can be used to make inferences about that population.

RFP (Request for Proposals)

An open and competitive process for selecting providers of services (sometimes called RFA or Request for Application).

Resource Allocation

The Part A planning council responsibility to assign Ryan White HIV/AIDS Program amounts or percentages to established priorities across specific service categories, geographic areas, populations, or subpopulations.

Ryan White HIV/AIDS Treatment Modernization Act of 2006 (Ryan White Program).

Enacted in 2006, this legislation reauthorized the Ryan White Program, formerly called the Ryan White CARE Act.

SCSN (Statewide Coordinated Statement of Need)

A written statement of need for the entire State developed through a process designed to collaboratively identify significant HIV issues and maximize Ryan White HIV/AIDS Program coordination. The SCSN process is convened by the Part B grantee, with equal responsibility and input by all programs.

Section 340B Drug Discount Program

A program administered by the HRSA's Bureau of Primary Care, Office of Pharmacy Affairs established by Section 340B of the Veteran's Health Care Act of 1992, which limits the cost of drugs to Federal purchasers and to certain grantees of Federal agencies.

Service Gaps

All the service needs of all PLWH except for the need for primary health care for individuals who know their status but are not in care. Service gaps include additional need for primary health care for those already receiving primary medical care ("in care").

SPNS

see Part F

STD

Sexually Transmitted Disease

STI

Sexually Transmitted Infection

TA (Technical Assistance)

The delivery of practical program and technical support to the CARE Act community. TA is to assist grantees, planning bodies, and affected communities in designing, implementing, and evaluating CARE Act-supported planning and primary care service delivery systems.

Target Population

A population to be reached through some action or intervention; may refer to groups with specific demographic or geographic characteristics.

Transition

A process more than a time point. During the process of transition there may be times when transfer to new or different services, personnel or place of care occurs.

Some terms included in this glossary were taken directly from HRSA *The HIV/AIDS Program: Glossary of Terms*

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