

IMPROVING THE TRANSITION PROCESS FROM PEDIATRIC TO ADULT HIV CARE IN NORTH
CAROLINA: A PATIENT- AND FAMILY-CENTERED PERSPECTIVE SYSTEM DYNAMICS
MODEL

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ABSTRACT

Sue Lynn Ledford: Improving the Transition Process from Pediatric to Adult HIV Care in North Carolina:
A Patient and Family-Centered Perspective System Dynamics Model
(Under the direction of Andrea K. Biddle)

When the adolescent's journey to adulthood is compounded by a complex chronic disease such as HIV the young person and their caregivers are oftentimes overwhelmed by the multifaceted array of issues. HIV-infected youth must learn to navigate a complex health regime and the social stigma that is associated with HIV. Studies show that youth may lack skills and confidence to adapt to the impersonal nature of many adult care institutions, and adherence to care regimes and medications is frequently a challenge. The parenting of HIV-infected youth is also a challenge and caregivers often lack the support they need. Youth need transitional care that is supportive and empowers self-efficacy.

This study focuses on transition of care from the perspective of HIV-infected young adults and the parents/caregivers of HIV-infected adolescents with a goal of formulating a patient-family-centered set of recommendations. The study assesses the common barriers and predictors of successful transition of care from the perspective of those most affected. The three-phase qualitative research design assessed effective transition strategies. Phase 1 consisted of key informant interviews (KII) with HIV-infected young adults and family members. Phase 2 prioritized key themes from the KIIs and correlated existing recommendations from the American Academy of Pediatrics (AAP) Committee on Pediatric AIDS (COPA) and the literature review findings to formulate a system dynamics causal loop diagram. Phase 3 involved a Stakeholder Action Planning (SAP) Session composed of: HIV-infected young adults 18-25 years of age, caregivers of HIV-infected adolescents, and healthcare providers to address "sticking points" identified in the transition process. Findings were then triangulated to propose key recommendations from the individual- and family-centered perspective.

Summary of key findings revealed the top ten issues identified by the key informants: adequate medical insurance, family/caregiver support, individualized physical/mental healthcare plans, ongoing provider support throughout the transition, strong self-efficacy, patient centered medical homes with wrap-around services, electronic health records and technology support, age appropriate educational support, stigma issues, and career guidance and planning.

This dissertation is submitted in gratitude for God's grace to navigate a challenging period of time.

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for instilling into me the value of hard work and a love of people.

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LIST OF ABBREVIATIONS

AAP	American Academy of Pediatrics
ACA	Affordable Care Act
ACO	Accountable Care Organizations
ADAP	AIDS Drug Assistance Program
AHRQ	Agency for Healthcare Research and Quality
AJPH	American Journal of Public Health
AJPM	American Journal of Preventive Medicine
APHA	American Public Health Association
ART, ARV	Antiretroviral Therapy
CDC	Center for Disease Control and Prevention
CHAMP	Collaborative HIV Prevention and Adolescent Mental Health Program
CLD	Causal Loop Diagram
COPA	Committee on Pediatric AIDS
EHR, PHR	Electronic Health Record, Personal Health Record
HIPAA	Health Insurance Portability and Accountability Act of 1996
HIV, BHIV, PHIV	Human Immunodeficiency Virus, Behavioral (BHIV), Perinatal (PHIV)
HRSA	Health Resources Services Administration
IDU	Injecting Drug Users
IRB	Institutional Review Board
JAID	Journal of HIV/AIDS & Infectious Diseases
KI	Key Informant
KII	Key Informant Interviews
MCO	Managed Care Organization
MSM	Men Who Have Sex with Men
NACCHO	National Association of City and County Health Officials

NCMJ	North Carolina Medical Journal
NCPHA	North Carolina Public Health Association
PCMH	Patient Centered Medical Home
SAP	Stakeholder Action Planning
SCD	Sickle Cell Disease
SD	System Dynamics
SEM	Social-Ecological Model
PI	Principal Investigator
USCA	United States Conference on AIDS

CHAPTER 1: INTRODUCTION

A. Statement of Issue: Transition in Care for HIV-infected Adolescents

Transitioning HIV care and other health services (hereinafter referred to as "transition") is only one of many transitions that adolescents with human immunodeficiency virus (HIV) face. Adolescence is a time of tumultuous change even when there are no complex health concerns to address, but when the adolescent's journey to adulthood is compounded by a complex chronic disease such as HIV the child and their caregivers are oftentimes overwhelmed by the multifaceted array of issues that must be addressed. This study assesses how best to facilitate a transition that is as free of barriers as possible and enables improved health and social outcomes for youth and young adults with HIV. The study was conducted from the perspective of HIV-infected young adults and the parents/caregivers of HIV-infected adolescents.

As the HIV-infected adolescent population emerges, there is a distinct need to facilitate a clear pathway and a well-defined process to prepare them, their families, healthcare providers, policymakers, and others involved in their care and well-being. Attention must be focused on developing a stronger understanding of their unique health and social support needs and the potential barriers that preclude their healthy transition into adult HIV care. In most ways these youth and emerging adults are no different than others at this challenging adolescent phase of life with the associated complexities. Transition corresponds with adolescence, a phase that is typified by self-exploration and risk-taking behaviors such as sexual debut, short-term consecutive partners, and experimentation with alcohol and drugs.¹⁻³ However, HIV-infected youths must learn to navigate a complex health regime and the social stigma that is associated with HIV to protect themselves and to avoid transmission of the disease to others.

The quality of life burden and financial cost associated with the lack of appropriate interventions, programs, and coordinated care are extraordinary and further mandate the need to mediate poor outcomes.

The primary burden of service inefficiency is the diminished quality of life for HIV-infected children and their families. There is also the issue of HIV transmission associated with population health and the elevated local, state, and federal economic burden of lifelong healthcare. In 2010, the total lifetime direct medical cost of persons in the United States living with HIV was estimated to be \$9.5-\$15.7 billion.⁴ Like other healthcare expenses, these costs will continue to rise.^{5,6} The total for North Carolina¹ is estimated to be \$631 million.⁶

Adolescence is commonly defined as a developmental phase between childhood (under 10 years) and adulthood (over 19 years) characterized by physical, psychological, and social changes at the individual level. Within this timeframe, there is a wide range of developmental stages. Although 18 is the legal age of adulthood, adult behaviors are not necessarily fully adopted by then. The American Academy of Pediatrics (AAP) Committee on Pediatric AIDS (COPA) describes the instability and impulsive nature of adolescence as “a developmental stage characterized by immature concrete reasoning often manifested by denial of illness, a sense of invulnerability reflected by risk taking, and behaviors that are strongly influenced by peer norms. These characteristics all have potential to negatively affect the ability to adhere to complex medical regimens.”⁷

A Massachusetts study on transition framed the issues and the common factors for young people in simple terms. The youth, their caregivers, and their health providers are fearful of change because the process is complicated. There is no standardized process for transition, and no clear model; therefore, every institution has its own protocol. Additionally, youth lack the skills and confidence to adapt to confusing adult care institutions, and adherence to care regimes and medications is frequently a challenge. The parenting of HIV-infected youth is also a challenge. Most caregivers lack the support they need and there is often a dilemma of too much parenting or too little parental involvement. Youth need support as they assume control of their care.⁸

¹ The state-specific costs for new diagnoses of HIV infection in 2009 for North Carolina, which is based on the number of new HIV diagnoses (1,719 cases), is then multiplied by the lifetime treatment cost and is discounted to the time of infection for each new case.

In June 2013, COPA released recommendations for transitional care of pediatric HIV patients which promise to improve guidance and standardization of HIV transition care for providers.⁷ COPA offered tools for transitioning pediatric to adult care. The five important recommendations will be discussed later in this document.

B. Background

Nationally an estimated 22% of persons ages 13–24 living with diagnosed HIV infection were infected through hemophilia, blood transfusion, birth, or unknown transmission mode, or infected perinatally.⁹ The majority of the HIV cases, however, are behaviorally transmitted via having unprotected sex with someone who has HIV.¹⁰ Gender and race also make a difference. Males are three times more likely to be infected, and 77% of HIV diagnoses were attributed to male-to-male sexual contact whereas 13% were due to perinatal exposure. In young women, 56% were attributed to heterosexual contact and 34% to perinatal exposure.¹¹ African Americans account for an estimated 44% of all new HIV infections among adults and adolescents (ages 13 years or older) in 2010. Although African Americans represent only 12% of the US population, this ratio represents a population rate that is 8 times that of the white population.¹² These national trends emphasize the need to address HIV in adolescents and young adults to prevent further spread of HIV to this high risk population.

HIV in children and adolescents continues to present a unique set of challenges for HIV-infected children, their families, healthcare providers, and public health around the world as well as here in the United States. Seropositive HIV infection in the pediatric population necessitates a highly coordinated and specialized system of care to achieve the best client outcomes.^{7,13,14} Distinctive age-appropriate prevention and intervention strategies tailored to the pediatric and adolescent HIV-infected population must differ in many key areas from the standard practices utilized for the adult HIV-infected population. Although this research is focused on the transition process in North Carolina, one of the better definitions for transitioning HIV care is from the global HIV/AIDS project AIDSTAR-One, which supports the efforts being made by many countries in the world to provide youth health and social support services well into their 20's.³ Several of the key informants in this research validated the point of waiting until the

age of 21-25 years of age for transition; one interviewee said, “There’s a lot of growing up goes on between 16 and 25.”

The Centers for Disease Control and Prevention (CDC) report that young populations account for 39% of all new HIV infections in the United States. For comparison's sake, persons ages 15–29 comprised 21% of the US population in 2011. The highest number of newly diagnosed infections was among the 20-24 years of age group with 6,237 new infections. The majority of these infections are believed to have been transmitted during the teen years. The *CDC HIV in Youth* report reveals an unsettling trend among youth in the United States. An estimated 8,294 young people ages 13-24 were diagnosed with HIV infection in 2009 in the 40 states with long-term HIV reporting. This age group represents approximately 20% of the persons diagnosed during that year. Seventy-eight percent of these diagnoses occurred in young people ages 20–24 years; young black men who have sex with men (MSM) have the highest incidence, accounting for 55% of new infections.^{9,11}

Because of improvements in antiretroviral therapy (ART), very few perinatally infected children are born in the US. Fortunately, children who are perinatally infected and children who are behaviorally infected now survive into adulthood and have the potential to live a full lifespan if properly treated with ART.¹⁵ HIV is considered by most to be a chronic health condition if under the proper care.¹⁶ Since the mid-1990s, the introduction of ART greatly extended the life expectancy of people living with HIV and has caused a dramatic drop in AIDS deaths.¹⁷

Children born with HIV in the 1990’s are now transitioning into adulthood. With the increase of HIV infection in the 15-24 age groups from behavioral infections, North Carolina can anticipate an ongoing need for adequate transitional care. In North Carolina, as of December 2012, there were 313 known pediatric cases (birth to 19 years of age) including 73 children birth-13 years of age and 240 children ages 14-19 years.¹⁸ If the older group (i.e., 20-25 years of age) is included, the number of HIV-infected youth increases tremendously; many individuals in this age group were infected during their teen years. These children/adolescents will be transitioning from pediatric HIV care to adult HIV care in the coming years. Multifaceted issues will be part of the transition process for these children/youth, their

families, and their medical providers. This study explores from their point of view how to improve the transitional process.

In 2011, North Carolina's newly diagnosed infections among adolescents and young adults varied according to gender and causative factors. Among males, the young MSM and injecting drug users (IDU) accounted for 79% of new HIV disease cases. Among the adult/adolescent females 92% of HIV cases were attributable to heterosexual contact, and 8% were from injecting drug use. Overall, 20% of all newly diagnosed HIV disease cases were among adolescent males, 13 to 24 years old.¹⁹

The combination of factors surrounding adolescence and young adulthood places these individuals at high risk of contracting and transmitting HIV. Physical changes, impulsiveness, denial of illness, a sense of invulnerability, increased risk taking behaviors, behaviors that are strongly influenced by peers, as well as the disconcerting new sexual impulses, create a climate that demands a continuum of care to assure the safety of the HIV-infected youth and also to prevent possible disease transmission to others.

C. Perspectives of Health Providers, HIV-infected Individuals, and Caregivers

Differing factors and opinions contribute to a variety of issues that must be considered by healthcare providers as they assist in the successful transition planning for young HIV-infected patients. Although most practices indicate that they do discuss transition, the related research indicates that there are seldom written medical plans and that the transition is less than an optimal formal process. The pathway to adult care is often wrought with challenges.²⁰ The primary concerns are related to the patients' continuity and quality of care while circumnavigating complex medical systems and social service agencies, and while simultaneously opening up communication channels with their providers.^{7,21-23} Even when there is adequate medical provider planning, the psychosocial factors and medical plans may not be sufficient to implement successful transition for HIV-infected adolescents and young adults. Often the unmeasured individual factors, such as relationships with caregivers and health support staff, and self-efficacy, may have greater impact on successful transition.²⁴ Furthermore, current payer systems do not

always facilitate an uninterrupted care pathway, and financial instability is an added obstacle. Financial insecurity is a big reason for depression among those with HIV. Additionally, many young adults lose health insurance coverage as they “age out”, with this loss adding to the chaotic transitional process.²⁵

The need to address the systemic factors that influence individual and family response, including how the healthcare provider and support staff may influence the transition process for HIV-infected youth and facilitate an improved transition could yield far-reaching benefits, both for the infected youth and also for population health by decreasing transmission rates for this at-risk population. Adolescents with HIV present distinct challenges for healthcare providers and many HIV-infected youth are initially diagnosed and cared for by pediatricians and their staff.

Again, the incidence of HIV in adolescence and young adults is disproportionately elevated accounting for 39% of all new HIV infections in the United States.¹¹ The implications of this high incidence indicate a serious gap in the continuum of care for HIV-infected individuals. CDC estimates that only 28 percent of the more than 1 million individuals in the U.S. who are living with HIV/AIDS are fully benefiting from treatment and therefore not likely to manage their disease and keep the virus under control.³ The growing evidence that “treatment is prevention” for HIV increases the promise of preventing transmission of HIV if adherence to ART is achieved; accordingly CD4 counts will be maintained and viral loads will decrease.²⁶⁻²⁸ To decrease transmission of HIV, adherence and continuity in care must be meticulously managed during transition. The COPA describes the instability and impulsive nature of adolescence as “a developmental stage characterized by immature concrete reasoning often manifested by denial of illness, a sense of invulnerability reflected by risk taking, and behaviors that are strongly influenced by peer norms. These characteristics all have a direct negative effect on the ability to adhere to complex medical regimens.”⁷

Transition for adolescents and their caregivers differs for each individual although there are certain predictable hurdles during the process. Disclosure is a very challenging process for parents and young HIV-infected young person. For those adolescents who are perinatally infected, the process often starts with the parent’s partial disclosure to the child.²⁹⁻³³ For the behaviorally-infected adolescent, there is

also the challenging hurdle surrounding the topic of disclosure and at times status may not even be shared with parents initially.^{3,8,29,34-38} The act of transitioning to adult HIV care is a long-term process and is not bound to a particular age.²⁴ Age-appropriate transition must be based on developmental readiness, maturity, and responsibility.¹⁴ Differing factors and opinions attribute a variety of dynamics to successful transition. Barrett et al.²⁴ indicate that psychosocial factors may not significantly affect successful transition for HIV-infected adolescents and young adults, and propose that the unmeasured individual factors such as relationship with support staff and self-efficacy may have an even greater impact on successful transition. They also add that future studies should explore the individual factors, including how the healthcare provider and support staff impact the transition process in HIV-infected youth in their successful transition.²⁴ Findings from the current study would support Barrett's theory that an array of individual factors have significant impact on positive outcomes.^{39,40}

As stated by Fair et al., significant differences exist between pediatric and adult HIV clinic models. Adequate planning and groundwork is critical for successful transition.¹³ Recently released recommendations from the American Academy of Pediatricians provide new established guidance on the transitional steps necessary for healthcare professionals who care for HIV-infected youth. Other groups such as AIDSTAR-One emphasize the access to HIV testing and counseling, the need for sexual health guidance, and psychological care; ART supervision and medication adherence strategies are also foundational for transition. "Transition programs must be tailored to a patient's individual capacities, readiness, and developmental age. A 'one-size-fits-all' approach will not work."⁴¹

The important role of the caregiver during the transition is also a determining factor. Parents are often challenged to know when to help and when to back away and encourage independence for the young person. Transition for adolescents and their caregivers differs for each individual and research on adolescence supports a multifaceted approach for HIV care that treats the person and not only the infection. Although HIV can be compared to many other chronic diseases that require age-appropriate transitional planning, stigma is a major factor for parents, children, and young adults. Parents and youth describe great difficulty with disclosure of their HIV status.^{14,42} Teens and young adults require

individualization of care that can address their unique sexual experience, relationships with peers, and often a casual attitude toward sex.

D. Significance of Issue

To break the cycle of transmission and to decrease the human and societal impact of HIV in youth, the multifaceted issues associated with the disease must be approached systematically. If optimal individual and social health outcomes are to be derived, improvement must be realized in every element of care.¹⁵ Silos of care and strategies that do not integrate across the service systems leave the adolescent in transition with outcomes that are less than desirable. Due to the complexity of the issues associated with transitional care for HIV-infected youth, the perspective of the various stakeholders and the key factors associated would benefit from a systemic analysis. Systems science has yet to be applied to the study of transitional care for HIV-infected individuals, their families, and the healthcare providers who care for them. The systems science methods are designed to address complex processes that change over time, are nonlinear in relationships, may be bidirectional (causal feedback loops), and may have time-delayed effects, as well as emergent properties or phenomena that are observed at the system level.⁴³ The inability to link one or two specific issues directly to an outcome requires a systems analysis to better understand and plan strategic interventions along the path and best influence improved outcomes.

E. Research Objective

The research objective is to assess the common barriers and predictors of successful transition from pediatric to adult HIV care in North Carolina from the perspective of those most affected (HIV-infected individuals and the parents/caregivers of HIV-infected children).

CHAPTER 2: REVIEW OF LITERATURE

A. Methods and Results

Search strategies for this systematic literature review focused on articles that offered insight and approaches to improve care coordination and health outcomes for HIV-infected children and their families. The topic of HIV is highly published; therefore, the literature review employed narrow date parameters (2008-2015) to capture the most recent and relevant published articles, although some highly relevant articles prior to 2008 were included. Articles were also chosen based upon the potential to facilitate improved transition for pediatric to adult care and/or possible barriers to the transition in care. Literature that provided evidence regarding proven or promising practices and single- or multi-dimensional approaches that address the needs of HIV-infected children and families was included. The articles could address issues with children or adolescents who acquired HIV either perinatally or via behavioral infection. Additionally, articles that dealt with the various components of wellness— physical, emotional, and behavioral health issues of children, adolescents, or their family—were noted.

Three primary search engines were utilized for key word searches: EMBASE, Google Scholar, and PubMed. The literature was initially identified using a broad array of key terms related to adolescent HIV, transition of care, behavioral health issues, family and relational care, health providers, substance abuse, medication adherence, preventive measures, risk-taking behaviors, and others. Key words included: “HIV”, “pediatric or (children, adolescent)”, “transition of care,” “community,” “intervention,” “prevention,” “disclosure,” “foster care,” “adherence,” “family,” “cost,” “system dynamics.” EMBASE was highly effective and often had a more extensive number of relevant articles. EMBASE allowed additional selective filters which proved to be useful for a highly published topic such as HIV. EMBASE was also more user-friendly due to ease of importing articles into RefWorks. PubMed was also an effective search engine and provided the added feature of *Related Citations*. I ran *Related Citations* on a

limited number of highly relevant articles and found this method to be an effective tool to identify articles that otherwise were not in the EMBASE or PubMed searches. Google Scholar was also utilized in a similar manner. Although websites are not generally considered for literature reviews, many of the highly relevant surveillance and evidence-based topics were not included in the review of EMBASE and PubMed. Therefore, a review of the CDC website was utilized due to the agency's extensive work with the topic of HIV.

The PubMed search revealed a large number of articles on pediatric HIV; therefore, as mentioned the scoping was refined to a more specific timeframe (2008-2015) to assure the most current and relevant materials were thoroughly reviewed. A limited number of "related articles" published prior to 2008 were utilized when they were identified as being highly relevant to the purpose of this research. The literature review was limited to articles on pediatric patients or young adults and English language articles. Initially the articles were limited to those articles that were specific to developed countries. Later in the review some examples from developing nations were analyzed. AIDSTAR-One is one such example; their literature on HIV transition to care in Sub-Saharan Africa was highly relevant. Scoping the literature revealed some important new information on the pediatric to adult transition process and as well as some significant gaps in research materials. The majority of literature on recommended practice for HIV transitional care was from the healthcare provider's perspective and segmented into relevant but fragmented interventions and programs.^{1,3,15,21,22,44-57} Most articles focused on only one or two of the key concepts, thus begging for a comprehensive system dynamics approach to improve care and outcomes for HIV-infected children and their families. The June 2013 AAP COPA report, however, brings forward the newest set of recommendations for transitional care and serves as the foundational platform for this dissertation research with HIV-infected young adults and their families.

Additionally, the literature review was refined to address two primary content areas important to this dissertation. Part I addresses the general topic of HIV in adolescents and young adults as they transition to adult care. As a foundation for studying HIV transitional processes and issues, this review begins with a summary of the key findings related to this topic. The effort also included transitional

processes for children with other chronic diseases. Part II of the literature review examines the general topic of system dynamics and the review of various health issues and systems that influence outcomes. Emphasis is placed on how socio-ecological systems impact the planning for a transitional plan for HIV-infected adolescents, young adults, and their families.

B. American Academy of Pediatrics (AAP) Recommendations

In June 2013, the American Academy of Pediatrics (AAP) Committee on Pediatric AIDS offered the following guiding recommendations for transitioning pediatric to adult HIV care. This recently published report proposes five important recommendations (pp. 196-197):

1. Pediatric, adolescent, and family medicine HIV care providers, in collaboration with suitable adult HIV care providers, should develop a formal process for transition from youth to adult healthcare.
2. The patient and his or her family should be introduced to the concept of transition to adult healthcare early in adolescence well in anticipation of the actual transfer of care. The youth should be informed of his or her HIV status before initiating the process.
3. The transition process involves 4 key steps:
 - a. The referring provider should develop written policies to define the process of transition of HIV-infected youth to adult healthcare. The plan should be shared with all pediatric/ adolescent or family medicine providers, staff, and patients and their families with appropriate staff training. Written documents, such as brochures and Web-based information, can be helpful in implementing the policy. Providers should establish a system to identify and track youth as they progress through the transition process.
 - b. The provider, the youth, and the family should jointly create an individualized transition plan well in anticipation of transition, which should include creation of a portable medical summary and/or electronic health record (EHR) and an emergency care plan. Providers may use a readiness assessment tool, and the transition plan should be revised on the basis of these assessments.
 - c. Transition to the adult HIV care provider should be initiated with appropriate communication, including a transfer letter and portable medical summary. A pre-transfer visit by the patient to meet the adult healthcare provider can assist in establishing a successful long-term relationship.
 - d. Completion of the transition should be documented, and the outcome of the process should be evaluated. The referring healthcare team should be available to the adult healthcare provider to serve as a resource during the immediate post-transfer period.
4. The healthcare coverage of the youth should be evaluated regularly to ensure that healthcare coverage and access to medications remains uninterrupted during transition.
5. The transition process should ensure that the youth's healthcare, educational, vocational, and social service needs are discussed and addressed.⁷

The June 2013 release of these AAP COPA recommendations provides new guidance for healthcare providers. The anticipated next steps will be adoption into practice for those providers who care for HIV-infected children and young adults. Previous research on other transition plans for children with chronic conditions such as sickle cell disease (SCD) found that although 89% of healthcare providers agreed that a systematic transition process was needed, only 67% of practitioners reported any transition activity.⁵⁸ Moreover, the providers who accept young patients with SCD find transitional care is poorly coordinated, and they report communication or adherence issues with teen or young adult patients that often results in interruptions between pediatric and adult care that exacerbate SCD crises.⁵⁹⁻⁶² At this time, no studies to assess the level of adoption of the AAP COPA recommendations in North Carolina have been conducted, and the majority of the NC-based research findings provide primarily the perspectives of pediatric and adult infectious disease care providers.^{13,21}

Markers of successful transition in care have also primarily been viewed from the medical model perspective with few studies that reflect the patients' social, mental, or familial perspectives.^{1,21,47,55,63-67} Providers who care for HIV-infected youth typically identified both behavior and serologic indicators of successful transitions. Behavioral indicators included keeping appointments, medication adherence, and demonstrating ownership of medical care. Providers also identified serological markers of a successful transition, specifically viral load and CD4 count.^{13,21} Several studies did assess "readiness" as a valuable perspective of youth transition. Weiner et al. used the "Transition Readiness Questionnaire" which assesses obstacles to a successful transition including identification of an adult care provider, access to medical insurance, and knowledge of disease status and medications.⁶⁸ These findings also were reflective of the medical providers' perspectives.

The literature review identified a transition questionnaire that could be easily modified for HIV-infected youth: the Jacksonville Health and Transition Services College of Medicine, Transition Readiness Assessment Questionnaire.⁶⁹ A modified version with HIV-specific queries is included in the plan for change section of this paper.

My research employed findings from the literature review and the AAP COPA recommendations to formulate questions for the key informant interviews for HIV-infected young adults and parents/caregivers of HIV-infected adolescents. Table 1 outlines both the nine key factors to consider in coordinating care for HIV-infected adolescent and young adults, and the number of articles identified in the review as examining each factor.

Table 1: Nine Key Factors to Consider for Coordination of Care for HIV-infected Children

Factor	Number of times cited in articles
1. Mental/behavioral health and substance abuse factors	40
2. Multi-modal or multi-dimensional care elements	28
3. Primary and secondary prevention efforts	23
4. Family/caregiver involvement	23
5. Transition planning from pediatric to adult care	21
6. High incidence in African American children	17
7. Disclosure of status	11
8. Foster care and incidence of child abuse/ neglect	10
9. New technology methods to improve adherence and prevention	10

Part II of the literature review examined the general topic of system barriers and the dynamics that influence health outcomes for children with chronic diseases. Emphasis was placed on the social ecological systems affected in the transition planning process for HIV-infected adolescents, young adults, and their families.

From the healthcare perspective, the primary barrier to successful transition was the lack of, or poorly coordinated transitional planning. Issues included no written plan, poor communication mechanisms between pediatric and adult providers, and no formal healthcare team responsible for the transition.^{25,50,59-62,70-75} These factors were consistently reported across the studies for transitioning of children with chronic diseases such as cystic fibrosis, diabetes mellitus, sickle cell disease, and other chronic illnesses. Very few articles on HIV transitional process currently exist, but congruency was evident in the available studies.^{3,7,22,23,45,50}

Another systems issue identified was the need to consider developmental age rather than simply basing transitional plans on the chronological age of the adolescent. As adolescence is a period of intense physical, psychosocial, emotional, and cognitive growth, there can be great variability in teens as they mature.^{25,64,71,76} Lack of training in adolescent development has been indicated as a significant barrier to the implementation of effective transitional programs. The time sequence for transition is very dependent upon the developmental level of the youth; accordingly, third party payers, malpractice coverage for pediatric practices, and convenience of timing often do not align with this reality.

Other barriers noted were issues such as deficiency in knowledge for disease management among the receiving provider and the transitioning young adult and their caregiver/parent. Healthcare providers may also need training and preparation to receive the complex care responsibilities. One study of general internists, for example, found that only 32% felt comfortable being the primary provider for HIV-infected individuals. In many rural areas of North Carolina there are few, if any, specialty adult primary care providers available for challenging health issues such as HIV.^{25,60,63,70,74,75}

Also, issues related to financial obstacles were noted in the literature. Financial independence, self-advocacy, and decision-making experience is an expectation in adult healthcare settings. Young adults also frequently deal with changes to healthcare payer systems, at times losing insurance coverage and potentially jeopardizing their care due to the inability to pay for services.^{61,77} Loss of coverage for periods of time is not an infrequent issue. Additionally, the reimbursement systems may decrease the willingness of adult healthcare providers to see complex care patients, whose care can be time-intensive and less lucrative than that of other patients.^{25,78,79} Part II of the literature review summarizes the system barriers identified for children with chronic diseases during transition to adult care in Table 2.

Table 2: Part II Literature Review Findings and Key System Barriers Identified for Children with Chronic Diseases

System Barrier	Health Provider	Patient/Family	Suggestions to Decrease Barriers
Poorly coordinated or inadequate	X		Assure well-coordinated written and verbal transition plans that provide gradual transition and have guided

transition plan (no formal or interdisciplinary transition team and lack of verbal and written plans)			expertise from a multidisciplinary team.
Must consider developmental age (rather than chronologic age) should guide transition	X	X	Assess predictors of success and advocate for transition readiness to guide transition. Assure multidisciplinary team is involved with transition.
Adolescents and family may lack knowledge and self-advocacy skills and lack of educational tools and resources to support transition	X	X	Multi-modal, gradual plan that assures access to important transition benchmarks and guidance on self-advocacy.
Receiving adult healthcare providers may also lack adequate knowledge of the disease and care recommendations	X		Seek progressive healthcare providers to offer educational support during and after transition.
Financial factors (Inadequate payment, reimbursement system inadequate, or loss of insurance coverage)	X	X	Advocacy and education regarding the financial factors that influence transition.
Fewer interdisciplinary support services and less expectation of familial support in adult-care settings	X		Consider partnerships among interdisciplinary services and active engagement of familial support in adult systems.
Parents of a patient are not actively involved in the transition	X	X	Active engagement of parents/caregiver during transition program.

program			
No formal forum for peer support and family interaction	X	X	Consider enhancement of peer support and forums for to increase interaction among families and young HIV-infected individuals.

C. Limitations of the Review Process

The studies have added valuable insight into the clinical perspective of transitional care for HIV-infected adolescents. However, there has been limited study on the HIV-infected young adult and familial perspectives. Also the system dynamics that impact the transition from pediatric to adult HIV care have limited discussion in the literature. The literature review revealed research gaps that confirm the need for additional study in these areas. Although a substantial amount of literature on HIV research exists, the inquiries seem to be siloed into relevant, but fragmented interventions and programs. Most articles focus on only one or two of the key concepts, thus begging for a comprehensive approach to improve care and outcomes for HIV-infected children and their families.

The Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMP) states that “grim reality becomes a serious public health issue as youth transition through adolescence, a time of increased experimentation with sexual risk behavior and drug use.”⁸⁰ For those adolescents who are already HIV-infected there must be a highly integrated system of care to protect their health and the health of the population they are part of.

Significantly, the other major take-away from this literature review is the lack of research based upon the perspective of the HIV-infected patient and his or her family. The current fragmentation and the lack of a cohesive, patient-centered model is likely a contributing factor to less than ideal outcomes for this population. There is a definite need for predictable and sequential plans that can be individualized for this population of HIV-infected children, adolescents, and their families. Although the new AAP transition recommendations are a welcomed addition for guidance among health providers of HIV-infected children, there is still a gap in strategy from the perspective of individuals most affected, HIV-infected children and young adults and their families.

No articles were found on “systems science and HIV transition.” The potential to provide a transition model that is based on the social-ecological model, which is cited throughout public health and CDC literature,^{81,82} and the systems that influence the family and individual perspectives for program and protocol development exists. This review informs that process. The need for clear guidance and directives for individuals, their families, and their healthcare providers is imperative. To improve health outcomes both at the individual level and for the greater good of the population, clear strategy and protocol to guide this volatile stage of transition is crucial. Alignment of the strategies for individuals affected and the healthcare system that serves this population is at a critical juncture with potential to reverse this decades-long epidemic. To stop the ongoing proliferation of HIV, controlling the disease among those individuals ages 15-24 could hold promise of significant reduction of HIV in the United States. The impact of this research has potential to be far-reaching.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

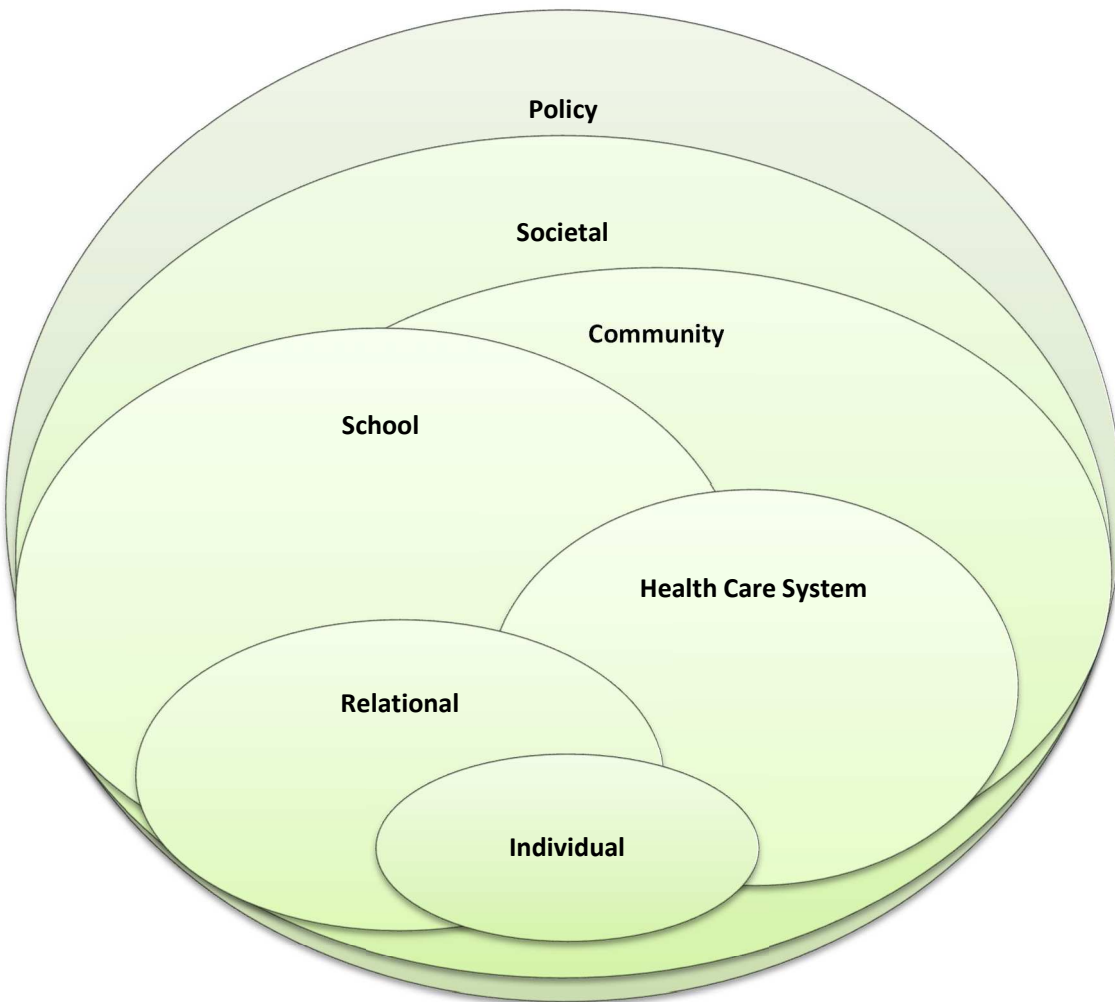
A. Conceptual Framework

This study applied the social-ecological model (SEM) which is widely utilized in public health.⁸¹ The multi-faceted model (Figure 1) is grounded in the premise that sustainable, positive health outcome change requires a systems approach. The SEM conceptualizes health determinants broadly and is inclusive of multiple factors that affect health. The SEM recognizes that health is affected by the interaction between the individual decisions, the group/community interaction, and the physical, social, and political environments.⁸³ This study incorporates the healthcare system and educational factors due to the age group in question.

Use of the SEM among public health professionals is generally for the purpose of identifying health factors that contribute to health outcomes. These factors include the individual, the interpersonal/relational level, the healthcare, community, society, and policy (Figure 1). These factors are then analyzed in depth to develop methodologies that prevent disease and promote improved health outcomes for individual health and population health.

In this study of the transition process from pediatric to adult HIV care, the research primarily focuses on the individual, the family relational aspect, and the healthcare system dynamics of the SEM. The intent is to consider the influence of various interrelational factors for HIV-infected adolescents and young adults in transition, and the research methods to be utilized for this study will be centered on this particular spectrum of the SEM. Although research in general is more likely to be focused on the individual and interpersonal characteristics shown in the SEM, this current research will also be attentive to possible, community, or policy factors that could positively influence outcomes for HIV-infected adolescents.^{81,82,84,85}

Figure 1: HIV Transition Social-Ecological Model



B. Specific Aims and Research Objective:

The overarching research objective is to learn how to better support HIV-infected adolescents in becoming healthy independent adults. While AAP COPA recommendations guide clinical practice through transition to adulthood, this research seeks to integrate those recommendations with insights from the literature and stakeholder engagement to guide more holistic system improvements. Specifically, this

research seeks to improve and integrate understanding of what is most needed to support transition based upon the HIV-infected young adult and family perspective.

AIM 1: To understand the most important factors shaping transition outcomes among HIV-infected young adults and their families through conducting ten semi-structured key informant interviews with HIV-infected young adults and/or parents/caregivers of HIV-infected pediatric clients.

AIM 2: To develop a more holistic understanding of how factors crossing socio-ecological levels come together to shape outcomes through adolescence and young adulthood by using system dynamics causal loop diagramming² to integrate insights from the literature review, AAP COPA guidelines, and key informant interviews conducted in Aim 1.

- Assimilate key findings from literature review, AAP COPA guidelines, and KII transcript key themes, then document all causal linkages (i.e., when a change in one factor leads to a change in another factor over time –ripple effects).
- Develop a causal loop diagram to integrate all causal linkages.
- Review, iterate, and affirm resulting causal loop diagram (CLD) with three key informant interviewees for key themes.

AIM 3: To work with a stakeholder action planning (SAP) group to prioritize identified targets from Aim 1 and Aim 2 for intervention, to brainstorm needs, and to develop action steps to improve outcomes among HIV-infected young adults. The process involved three stages:

- Convened the stakeholder group (HIV-infected young adults 18-25 years of age, caregivers of HIV-infected adolescents, and healthcare providers) to review work from Aim 1 and Aim 2; introduced background process, causal loop diagramming, system approach, and key themes from findings.
- Prioritized the ten broad leverage points (priority areas) identified in Aim 1 and Aim 2 through use of prioritization exercise. For each of the ten priority areas, discussed the dynamics in depth and elicited action steps or targets for which action is most needed. From the CLD, a list of all relevant factors was developed for each priority area and discussed in detail. Stakeholders were asked what action could be taken or was needed related to each target variable.

² System Dynamics tools such as casual loop diagrams (CLD) illustrate various factors that influence health outcomes. Using a simple design of supporting or opposing factors the CLD demonstrates the nature of impact or the relationship between factors in health outcomes.

- Based on insights from the stakeholder action planning session, a concrete plan for change was developed.

C. Study Approach and Design: Design Overview

Research methods science recommends the triangulation of multiple data sources and studies to corroborate reliability of findings.⁸⁶ The triangulation of methods is well suited for system analysis and to adequately reflect the complex process of transition from pediatric to adult HIV care. Correlation of key factors that facilitate transition and identification of the major barriers to successful transition will yield recommendations from the patient-and family-centered perspectives for effective transition from pediatric to adult HIV care. Each aim employed an interpretive empirical research theory that analyzed the actual patient and/or caregivers' experiences during the transitional process from pediatric to adult HIV care.⁸⁷ HIV-infected individual's experiential context is crucial to the course of this research. This analysis is intended to emphasize the individual's "lived experience". By capturing qualitative findings that are based upon life experience and personal perceptions from the descriptions provided by HIV-infected young adults and caregivers of HIV-infected adolescents, the researcher was able to better understand which processes or actions facilitate transition and which processes or actions have deterred individuals and their families during the long transition process spanning from age 10 through age 25. The hope is to understand more fully the challenges at each level of the social-ecological stratum over the life course.²⁶ The reality of their responses and management of the day-to-day circumstances of transition has provided depth to the current medical model recommendations for transitioning of the HIV-infected adolescent.

The Research Triangle region of North Carolina, setting for the study, is an eight-county region in central NC and includes Raleigh, Cary, Durham, and Chapel Hill metropolitan statistical areas. The 2012 US Census estimates the area's population to be 1,998,808, and the area is ranked as one of the fastest growth areas in the United States.⁸⁸ Due to the population density the setting was conducive to conducting research with a diverse group of HIV-infected study participants. As of December 31, 2012 the NC Vital Statistics Division reports that 2,825 individuals were diagnosed with HIV/AIDS in Wake County alone. With the surrounding counties, there are an additional 4,404 HIV diagnosed individuals which totals

7,229 HIV cases in the region¹⁹. The exact number of HIV-infected individuals from birth to 25 years of age in the Research Triangle region is not defined by the state at this time; however, it can be extrapolated from the national statistics that approximately 20% or 1,445 of those diagnosed with HIV would be in this age group.⁹ As of December 31, 2012 there were 318 HIV-infected pediatric cases in NC from birth to 19 years of age; 240 of these are age 14-19.¹⁸

A three-phase qualitative research design with three primary aims was utilized for this project. The qualitative approach facilitated exploration of attitudes, experiences, and responses from the perspective of those individuals most affected by the transition experience. The inductive inquiry focused on the HIV-infected individuals and their families and synthesized the complex nature of the life circumstances they find themselves in as they transition to adult care.⁸⁹

Phase 1 (for Aim 1) consisted of semi-structured key informant interviews (KII) with 10 HIV-infected young adults and/or parents/caregivers of HIV-infected pediatric clients and was conducted in November and December 2014. KII participants were recruited with the assistance of Triangle region HIV care providers. Interviews were in person or by phone, and arranged to assure confidentiality and convenience of the interviewees. Recorded interviews were then transcribed and coded for key themes utilizing the NVivo qualitative analysis platform. The interviewees were found to be receptive and forthcoming with their responses and appreciative of the research intent to improve transition processes. See Appendix 1 for NVivo coded key themes and Appendix 2 for Causal Loop Coding Themes.

Interview questions incorporated the individual's "HIV experience story timeline" with inquiries such as, "Tell me the story of when and how your child was initially diagnosed with HIV?" or, "Tell me how you first found you were HIV infected," in the case of the 18-25 years of age group. Additional questions were based on themes from the American Academy of Pediatrics *COPA Recommendations on Transitioning HIV-infected Youth into Adult Healthcare*,⁷ and literature review findings. Table 1 in the previous chapter outlines the nine key factors that surfaced in the literature review: behavioral health issues, healthcare elements, transmission and prevention strategies, involvement of caregivers, cultural issues, disclosure of HIV status, transition planning, and technology in care process.

Also, the questions utilized the Fair et al.⁷ indicators of transition success, the Weiner et al.⁶⁸ identified barriers for transitioning, and the COPA recommendations to formulate questions for the key informant interviews.^{7,21,68} Following are examples of questions that reflect the recommended practices:

1. Will you discuss the transition process (formal process for transition) used by your pediatrician? And do you have a written copy of the plan?
2. Do you recall when your pediatrician's office first introduced the concept of transition to adult healthcare? Can you share how that was done?
3. When were you (as a youth) informed of your HIV status?
4. Was there an individualized transition plan that was jointly created (provider, the youth, and the family)? Did you participate actively in the plan?
5. Can you recall specific discussion regarding how the transition in healthcare would/will happen?
6. Were the topics of education, vocational plans, and/or social service needs discussed? Can you elaborate on these topic discussions?

In January 2015, the second phase of the study began by assimilating findings for **Aim 2**. The literature review, AAP COPA guidelines, and key informant interviews conducted in Phase 1 were compiled to address the various socio-ecological stratum. Each of the SE stratum shape outcomes along the life-course for adolescence and young adulthood. By using system dynamics causal loop diagramming we integrate these insights. The objective of the process is to reveal evidence of the reciprocal relationship of multiple factors in the social-ecological framework that contribute positively or negatively to the transitional process for adolescents and young adults living with HIV. Upon completion of the CLD, three key informant interviewees were enlisted to review findings and affirm results for key themes and to prioritize a top 10 list of issues. The list was then used to facilitate Aim 3 Stakeholder Action Planning (SAP) Session.

Moving into the third phase of research, the **Aim 3** Stakeholder Action Planning Session was conducted in February 2015. See Table 3: Agenda for Stakeholder Action Planning Session. The SAP session involved HIV-infected young adults 18-25 years of age, caregivers of HIV-infected adolescents, and healthcare providers. The setting was casual and fostered a respectful and welcoming environment for

the stakeholders. A trained facilitator along with the principal investigator began the SAP group discussion by introducing the group to the transition research background and objectives of the study to inform and to re-familiarize the stakeholders. Adequate time for questions and answers was provided throughout the process to assure understanding. Causal loop diagrams and system dynamics concepts were explained briefly to assure understanding of process. The SAP group was then led in a prioritization exercise of the top ten factors derived from the Key Informant Interviews (KII). Each participant was asked to determine the top three issues. Results from the exercises are reported in the findings section.

Table 3: Agenda for Stakeholder Action Planning Session

Task	Responsible	Time allotted
Welcome, introduction of today's agenda, confidentiality statement, and permission to record	Facilitator	10 minutes
Overview of research project, background and purpose of Transition Process review	Principal Investigator	10 minutes
Question and answer period, if needed	Research Team	10 minutes
Snacks and Ice breaker	Facilitator	30 minutes
Review of Key Informant Interview findings and Top 10 ranking exercise	Facilitator and Principal Investigator	30 minutes
Divide into sub-groups to review key finding categories	2 groups	30 minutes
Break	N/A	10 minutes
Re-unite group for final feedback – Connection Circle Exercise	Facilitator and Research Team	30 minutes
Closing comments, question/answers, and next steps	Facilitator and Principal Investigator	15 minutes

The discussion included the most challenging problem areas, the “sticking points”, and also the identified strengths. The first prioritization exercise for the group involved identifying the ten most important factors contributing to transition success. The discussion leader and principal investigator utilized the SD causal loop diagram technique to illustrate KI interview findings and to elucidate the

complex systems that affect transition (See Appendix9: Phase 3 Stakeholder Action Planning Session PowerPoint and Appendix 7: System Dynamics Model). The principal investigator began by reiterating that one must begin with the end in mind to understand the core components of healthy adolescent transition. Stable physical health and stable mental health reduce the risk of HIV transmission and improve outcomes for young people living with HIV. The principal investigator was then able to demonstrate how the KIIs had contributed to identification of the additional factors that shape physical and mental health.

The principal investigator diagramed the current context, and identified leverage points for consideration and potential solutions that push these leverage points. The group responded with their views and prioritized the *most challenging* of these problem areas while identifying methods to address the sticking points, see Table 4 Prioritization Exercise. Health literacy levels were taken into consideration as participant's educational ranges varied.

Table 4: Prioritization Exercise Form for Top Ten Factors of Successful Transition (Stakeholder Action Planning Session participants placed a dot on prioritized items.)

Family/ Caregiver support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adequate medical insurance coverage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A Patient-centered medical home with access to “wrap-around” services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Technology support and Electronic Health Records access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Individualized physical/ mental health care plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strong self advocacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Age appropriate educational support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Address stigma issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Career guidance and planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ongoing provider support for entire transition process (Medical and Bridge Counselor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Next the SAP group evaluated each of the top ten target areas and further ranked relevant themes for each. This group prioritization exercise (Table 4) synthesized the compilation of Phase 1 and the Phase 2 key findings from literature review, AAP COPA guidelines, and KII key themes. The SAP feedback provided prioritized findings and a finalized set of recommendations for transition. At the conclusion of the exercise feedback the group re-united to review results and allow further questions. The closing activity for the stakeholder's discussion was the "Connection Circle Exercise." The purpose of the connection circle, which is considered a promising practice,⁹⁹ is "to see important variable and connections between variables." Each participant engaged in the exercise. (Appendix 5 Stakeholder Action Planning Session, slide 23- Connection Circle) The product that resulted from the connection circle exercise was a chart drawing from each participant of their perceptions of how the systems should connect to improve outcomes. The final products from the SAP formulated the recommendation for transition from the key stakeholders' perspective. SAP group participants were all age 18 or older and were fluent in English. A \$25 gift card was provided to all participants other than health care providers to compensate for time and travel expenses.

Sample Selection and Recruitment Process: Participants were drawn from healthcare provider sites that serve HIV-infected pediatric and young adult clients in North Carolina's Triangle Region. Cultural diversity of the interview sample was consistent with the HIV population in this region. No one was excluded due to race, ethnicity, gender, or sexual identification.

Personal phone calls were made and emails were sent to the providers explaining the research intent and criteria for inclusion in the study. Recruitment of potential interview subjects was done by use of informational flyers placed in clinics and referrals from the HIV clinical practice providers. The selection of interviewees was based upon the first 15 individuals who responded. Subjects were given an email and phone number to contact the principal investigator. Although only 10 subjects were needed to complete the study, 15 were enrolled with the understanding that some may not be required to participate. A \$25 gift card was offered to offset the cost of travel to the interview site. After initial contact by potential subjects, the PI or research assistant made contact with subjects by encrypted email or phone to

provide a brief, standardized descriptive script of the study. All personal identifiers were omitted and interviewees were assigned a numerical identifier (WC01- WC10). When participants agreed to be interviewed, an appointment was scheduled at a time and location convenient to them. The meetings were private, conducted face to face, or by phone when necessary. All sessions were recorded with permission.

The decision to limit the interviews to 10-15 participants was based upon the concept of data saturation, which is important for qualitative research as it addresses content validity. Purposive sample size generally relies on the theory of an adequate “saturation” level which is the point at which no new information or themes are observed in the data. Research findings of Francis et al.^{90,91} indicated that data saturation and variability over the course of thematic analysis found saturation occurred within the first twelve interviews and basic elements for meta-themes were present as early as six interviews.⁹¹ Mason also reports that qualitative samples must be large enough to assure that the majority of the perceptions that might be important are revealed, but that data samples that are too large become repetitive, and eventually, superfluous.⁹⁰ It should be noted that this KI interview process began to reach “saturation” level after the first eight interviews.

Inclusion Criteria: Two groups were targeted for interviews—family members or caregivers of HIV-infected children and HIV-infected young adults 18-25 years of age. All interviews were conducted in English. All subjects were either related to, currently were caring for or had cared for an HIV-infected child/youth/or young adult, or were themselves a young HIV-infected adult 18-25 years of age. Subjects spoke English and were self-identified from clinics that provide HIV care.

Prior to the interview, consent to audio-record the interview was sought in order to assure that a complete transcript of the interviews was available. Also, brief handwritten notes of significant findings during the interview were kept. The “UCLA Center for Health Policy Research”⁹² model was used along with a printed, hard-copy template of key questions, leaving enough space between each question to manually write the key informant’s comments while conducting the interview. Immediately after the interview, while the information was still fresh, the written notes were proofed to avoid losing valuable characteristics and information from the interview.⁹² Transcription of interviews was contracted. The

interviews were conducted face to face, or by telephone when the subject was unable to schedule a face to face interview. Interviews were completed between October and December, 2014.

Subjects with less than two years of experience caring for HIV-infected children or young adults, parents of HIV-infected children less than 5 years of age, and non-English speaking subjects were excluded. The interview process took approximately 60-90 minutes and covered material in a 25-question, semi-structured interview protocol. The questionnaire followed best practice in design for interview protocol⁸⁹. Participants were advised that they would receive a final summary of the research findings and a thank-you statement to acknowledge their invested time and participation.

D. Data Analysis Process

The purpose of the research analysis was to provide an account of the complicated dynamics that young HIV-infected individuals and their families face as the infected adolescent transitions into adult healthcare. The goal is to formulate a patient-/family-centered set of recommendations for the care transition process.

Specifically, the qualitative, primary data obtained from the key informant interviews and the SAP group's evaluation of the prioritized HIV Transition Model required an iterative process of working backwards and forwards to assure that a comprehensive set of themes emerged. Creswell's book, Research Design: Qualitative, Quantitative, and Mixed Methods Approaches 3rd edition⁸⁹, describes an inductive process of generalizing themes which was utilized in guiding this research. The qualitative data were analyzed by reading the transcripts multiple times to identify major themes. The transcribed KII data were entered into NVivo platform, a qualitative data analysis software program, to further scrutinize the key themes and trends. Interview responses were divided by question and independently coded by the principal investigator and a research assistant for cross verification.

Both the key informant interview guide and the SAP group discussion were formulated based upon the perspective of the HIV-infected young adults age 18-25 and/or the family/caregivers of adolescent HIV-infected individuals. The final recommendations incorporate findings from all three

research phases (Aim 1-KIIs, Aim2- Causal Loop Diagram summary, and Aim 3- SAP group) and key stakeholders were involved in each phase to guide the findings. The correlation of the key factors that facilitate transition and identification of the major barriers to successful transition yielded recommendations from the patient- and family-centered perspectives for effective transition from pediatric to adult HIV care. The following subsections describe the data analysis process for each aim.

Aim 1: A less prescriptive key informant interview style assured ample opportunity to explore emergent themes from the interviews and overall research process. The interpretive inquiry process of qualitative research requires the PI to provide an explanation of what is heard and seen from the interviews with KIIs.⁸⁹ The interviewees' verbal responses and statements as well as their non-verbal cues were documented. The multiple views of the principal investigator, participants, and even the readers of the transcribed notes provide various interpretations of the questions and answers.⁸⁹ Repetition of themes (such as stigma or self-efficacy), transitions (such as accessibility of care and provider support), similarity (financial resources, insurance, and affordability of care), and differences were noted and coded. Key themes were also framed based upon successful patterns, challenges, and potential missing components to best understand barriers or issues. Relationships with family, community, and health providers were noted and consideration also was given to the segregation of responses from caregivers which varied at times from the responses of the 18-25 age group.

Coding analysis of relevant phrases, words, and concepts was completed and documented as discrete categories for connections between concepts utilizing the NVivo platform for qualitative analysis. Furthermore, phrases or comments that were confirmatory of the information identified in the literature review were coded as such. Coding tables were utilized to disaggregate and organize findings for each question (see Appendix 2: Causal Loop Coding Themes). MacQueen et al. offered a concise formula to structure coding using three components: code name/label, definition, and an example.⁹³ A similar method was employed: theme/ causal themes/ things that improve transition or control of HIV/ and things that worsen transition or control of HIV. MacQueen et al. also suggest that the primary responsibility for creating, updating, and revising coding needs to reside with a single individual (here the principal

investigator assumed that role). The coding scheme was kept as simple as possible by segmenting KI statements into themes (sentences or words) and citing specific quotes. As coding is an iterative process, there were multiple readings and reviews of the key informant interview responses.

Aim 2: During this phase of the research an iterative process of analysis and coding was used to review the qualitative data from the KI interviews. The NVivo qualitative data analysis software platform facilitated a method of organization and analysis of content from the various interviews. With the intent of developing a more holistic understanding of how the various factors influence health outcomes for HIV-infected adolescents and young adults, attention was concentrated on the KI interviews with cross-analysis of insights from the literature review and AAP COPA guidelines. As the key themes emerged they were outlined in table format to summarize causal theme categories, cross connections, factors that improve transitional process or control HIV, and factors that worsen transition or the control of HIV. See Appendix 2 Causal Loop Coding Themes for Causal Loop Diagram. The CLD started with the end in mind and evolved from the core components of healthy adolescent transition. Stable physical health and stable mental health reduce the risk of HIV transmission and improve outcomes for young people living with HIV. From that set of core components additional causal themes from the coding were integrated to demonstrate the various factors that shape physical and mental health.

The system dynamics causal mapping approach is utilized to facilitate understanding of non-linear processes or behavior in complex systems such as transitional care. The iterative modeling technique builds the CLD and aids visualization of how variables are interrelated and connect to shape outcomes.^{40,94} Three of the key informant interviewees were chosen to participate in a one-on-one assessment process to refine the key findings and transition factors. These key informants were chosen based upon their willingness to participate and the principal investigator's perception of their ability to generate useful substantive feedback. Each individual reviewed the draft CLD and the prioritized list of factors facilitating transition to assure clarity, congruency, and to identify any missing elements or themes. These one-on-one sessions were useful in refining the data and process that were employed in Phase 3.

Aim 3: Analysis of the findings from the SAP session discussions was based upon the collective feedback of four HIV-infected young adults 18-25 years of age, two caregivers of HIV-infected adolescents, and four healthcare workers. These participants divided into two subgroups to further prioritize the sub-category problem areas and to suggest methods to address problem areas (for more information, see Appendix 6 Stakeholder Action Planning Session, slides 8-22). Each group was assigned five of the top ten areas and asked to prioritize the sub-topic system issues which were previously derived primarily from Aim 2 compilation findings in the causal loop exercise.

Documentation of the discussion that occurred in the various groups/subgroups included flip chart notes, audio-recorded notes, written summary transcripts by principal investigator and research assistant of what was said, and descriptive narratives of the group interaction. Recordings were transcribed to assure that no crucial information was omitted.

The qualitative findings were analyzed with the assistance of a DrPH committee member, who also assisted with the group process facilitation (KHL). The findings then were assigned by the principal investigator to the key themes and categories based upon patterns or contrasts. The process included data reduction and analysis of contextual factors such as participant's age, infection status (behaviorally or perinatally infected), role (young adult, caregiver, or healthcare provider), socioeconomic status, race/ethnicity.⁹⁸ This cumulative SAP session data analysis was then assimilated into the final transition recommendations.

E. IRB Considerations

Ethics approval for the research study was obtained from the Office of Human Research Ethics at the University of North Carolina at Chapel Hill (IRB Study# 13-3405). The primary potential risk for participants was breach of confidentiality; there were no breaches during the research.

CHAPTER 4: RESULTS

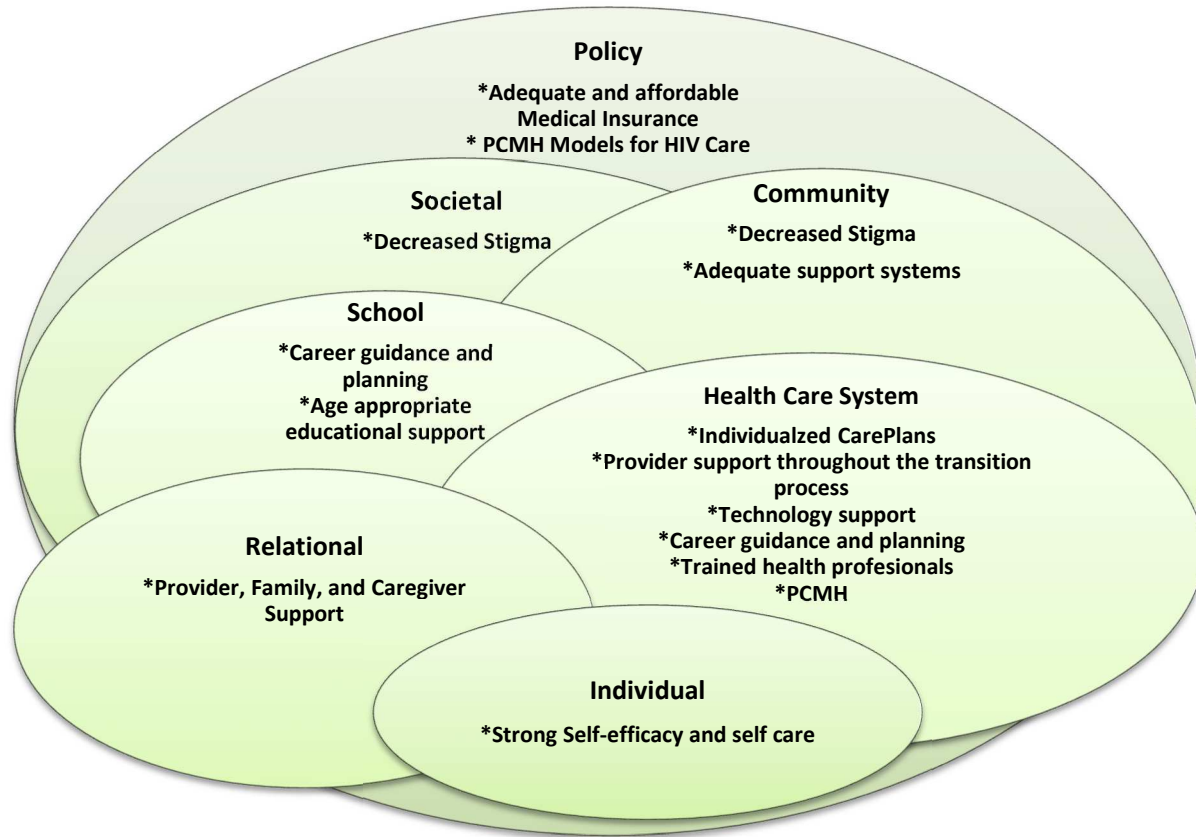
A. Involvement and Contribution of Stakeholders

Key stakeholders expressed genuine interest in the research on transitional care from adolescence to adult HIV care. Caregivers, health providers, and the HIV-infected young adults embraced the opportunity to offer meaningful contributions in the hope of impacting the complex systems that influence outcomes for young HIV-infected youth. Accordingly, the individual interviewees and the SAP participants were transparent and eager to share their input in the hope of improving life for HIV-infected youth transitioning to adult care in the future. One young interviewee lamented, “It’s the mix of everything, the money, the stigma, health problems, no insurance, remembering to take the meds, whether you have someone to help support you, you know, help you along the road. It’s a lot to juggle and it’s easy to get down in the dumps.”

B. Link to Conceptual Model

The research identified key factors were applied to the social-ecological model (SEM).⁸¹ By using system dynamics to develop a more holistic understanding of how factors crossing socio-ecological strata come together we can understand how the various levels shape outcomes through adolescence and young adulthood. The multi-faceted model in Figure 2 is grounded in the premise that sustainable positive health outcome change requires a systems approach. The modified social-ecological model informed by this research incorporates the multiple factors that can improve health outcomes for the transitioning HIV-infected youth.

Figure 2: Transition Social-ecological Model with Individual and Family Informed Key Factors



C. Key Findings and Recommendations

This patient- and family-centered research approach refined and prioritized a complex system of transitional factors to yield a list of the ten most important factors for successful transition from adolescence to adult HIV care. By engaging key stakeholders for input and compiling the KII findings, the AAP COPA recommendations, and literature-based key themes into a causal loop system dynamics diagram the complexity of the process was captured. Table 5: Summary of Recommendations for Successful Transition outlines the key factors per research findings. Detailed descriptives follow table.

Table 5: Summary of Recommendations for Successful Transition

Recommendations for Key Factor 1 Adequate and affordable medical insurance coverage

- Organized conversation with state and federal level policy makers to focus consideration on how to best align the various federal, state, and private market HIV health plans (Ryan White funds, ADAP, Marketplace plans, Medicaid, social service programs, private or employee insurance plans, co-pays, and medication plans).
- Coordination of plans could align and maximize resources to achieve improved outcomes in a more cost-effective manner. A modified HIV insurance plan may best be described as a patchwork system of coordinated options which customize plans for the individual and family needs.
- Trained social workers and bridge counselors can assist all HIV infected individuals in selection of plans that best meet their needs.
- Treatment of HIV is prevention and prevention is reduction in new infections.

Recommendations for Key Factor 2 Individualized physical and mental health care plans

- AAP COPA recommendations should be emphasized and a formal process of transition from youth to adult healthcare should be led by the referring provider and providers
- Equitable participation of the patients and their families in development of the transition plan must be assured.
- Written policies that define the process and assurances should be developed.
- Additionally, the plan should encourage input from the entire health team (mental health, social worker, bridge counselor, medical provider, etc.) and all health providers involved in the process should have access to the plan.
- Establish a system to identify and track youth as they progress through the transition process to assure key benchmarks are met.
- Patients, families, and other providers should have electronic access to the care plan
- Other factors to consider: possible comorbidities and mental health needs, plain language documents and health literacy experts should be included in development of the plan,
- Finally, it is recommended that evaluation of NC HIV pediatric providers to assess the level of adherence and utilization of the AAP COPA recommendations

Recommendations for Key Factor 3 Ongoing provider support throughout the transition process (medical and social worker or bridge counselors)

- Adhere to AAP COPA recommendations for referring healthcare team to be available to the adult healthcare provider during the entire transition and to serve as a resource during the immediate post-transfer period.
 - Young BHIVs need social work and bridge counseling support to assure care and assistance through the myriad of decisions, insurance planning, and service links.
 - Enhance improved outcomes and decrease HIV transmission by utilizing an acuity ranking scale to facilitate appropriate linkage to social workers or bridge counselors for high need young HIV-infected individuals.
 - Establish tracking mechanisms for transition process to assure key benchmarks are
-

met.

- Electronic access to the care plan for young HIV-infected individuals and their family.

Recommendations for Key Factor 4 Family and caregiver support

- Provider support and education for the family/caregivers of HIV-infected youth is part of an integrated care plan.
- Family involvement in the transition planning process to address potential family needs and enable the family/caregiver to focus attention on the needs of the youth.
- SW support for the difficult conversations and issues needed by the parents.
- Address and evaluate for the high potential for psychosocial stressors in the HIV family structure.

Recommendations for Key Factor 5 Patient-centered medical home (PCMH) with access to “wrap-around” services

- Encourage policy options for the transition of Ryan White (RW) services and federal funds to adapt to the new ACA Marketplace and the patient centered medical home (PCMH) models.
- Consideration of how to best align the various federal, state, and private market HIV health plans (RW funds, ADAP, ACA Marketplace plans, Medicaid, social service programs, private or employee insurance plans, co-pays, and medication plans).
- Clinics that limit care to only chronic infectious disease management should better align services with other agencies to assure wrap-around services for their patients.
- Training for existing RW clinics to encourage clinic structure and business plans that accommodate the new funding requirements
- Policy makers in NC should consider several important areas for action and research with regard to development new models of care such as HIV PCMHs.

Recommendations for Key Factor 6 Career guidance and planning for transitioning youth

- Career and vocational counseling should be a component of the overall case management for all HIV infected age 15-25.
- Assure this valuable function the social workers and bridge counselors to actively work with the youth and families.
- Funding sources could incorporate career/vocational mentoring into the responsibilities of HIV social workers and outcome measures.
- Public schools should reach out to health providers and social workers to link them with resources and scholarships.

Recommendations for Key Factor 7 Strong self-advocacy (self-efficacy)

- Assure the AAP COPA recommendations are utilized to prepare youth for transition early in process.
- Conduct readiness assessments that identify strengths, gaps, and inform education plans for youth and parent/caregivers.
- Continue link to outreach social worker to address the logistical and emotional stability for transition.
- Encouragement of education to aid self-efficacy.

- Assure appropriate access to electronic health records and awareness of how to navigate EHRs.

Recommendations for Key Factor 8 Must address Stigma Issues (among providers and community)

- Enhance self-efficacy training for local HIV providers to enhance the young person's communication skills with friends and providers.
- Assure providers and HIV-infected individual's skills to appropriately address concerns of HIPAA violation.
- Assure more pro-active educational outreach for medical providers in rural communities.
- Take legal action when necessary for known violations of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).
- Develop recommendations for role-playing "disclosure scenarios" that all young people living with HIV/AIDS have opportunity to be educated on legal requirements disclosure.
- Assure accurate disease process education and medication training to enhance self-efficacy.
- Explore option of peer navigators to act as mentors and role models to transitioning youth who are learning to cope with the daily challenges of living with HIV.

Recommendations for Key Factor 9 Age appropriate educational support (childhood to adulthood)

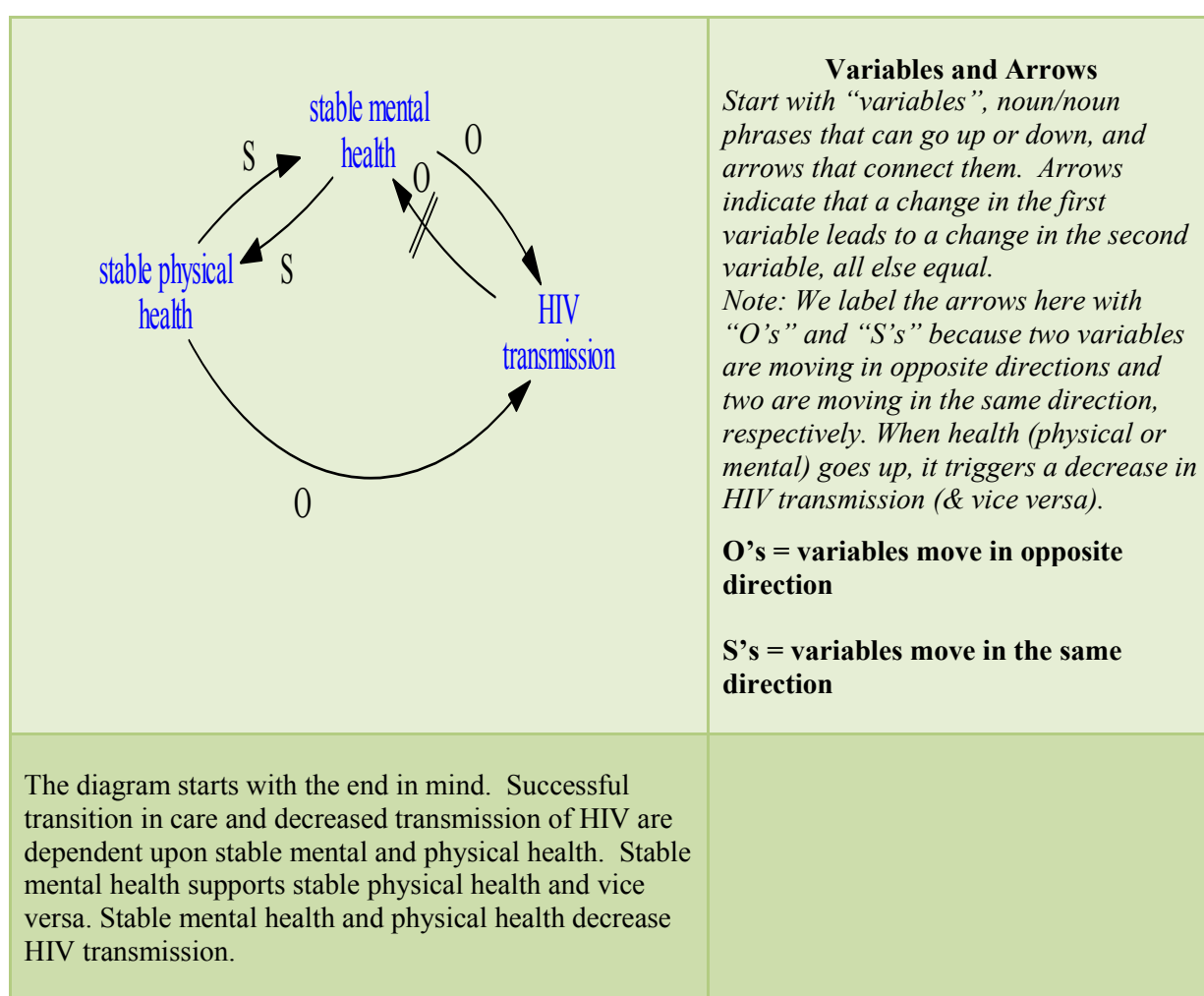
- Per the AAP COPA recommendations, the provider, the youth, and the family should jointly create an individualized age-appropriate written transition plan well in anticipation of transition.
- The written transition plan should include creation of a portable medical summary and/or electronic health record (EHR) and an emergency care plan.
- All providers of care for young HIV infected individuals, ages 16-25, should assure at minimum education on the following mandatory topics: HIV status disclosure methods and related legal requirements, safe sexual practices, associated medical treatment plans, appropriate insurance coverage, information related to ADAP and other resources, medication adherence tools, Career planning.
- It is also recommended that quality control measures be built into the various funding sources for HIV care to assure the minimal education requirements.

Recommendations for Key Factor 10 Technology support and access to electronic health records

- Electronic records must be accessible, understandable, updated in a timely manner, and compliant with Stage 2 Meaningful Use requirements.
- Training and support for patients is recommended to facilitate their ability to utilize the electronic records to their maximum benefit.
- Innovative technology solutions are also encouraged for the millennial generation.

Guided by the Stakeholder Action Group in Phase 3, the principal investigator prioritized factors perceived to be most important in improving physical and mental health outcomes for HIV-infected young adults and this holds promise of decreasing transmission of HIV into the population. Stable *physical* health leads to stable *mental* health, stable *mental* health supports stable physical health; both deter transmission of HIV. Figure 3 below reflects these core components. The core components are part of the more elaborate Causal Loop Diagram and are more fully detailed in Appendix 3.

Figure 3: Core Components of Healthy Adolescent Transition



Phase I, after the key informant interviews were complete, the iterative process of reading and analysis of the KI interview data identified multiple themes. These factors were then categorized and

refined into an initial list of 17 key themes utilizing the NVivo platform for analyzing qualitative data (See Appendix 1: NVivo Coded Key Themes). In Phase 2 the themes and the supporting or opposing elements were plotted into a SD causal loop diagram to further explore the interrelationship of various factors. Additionally in **Phase 2**, three of the original key informants participated in an iterative process to generate substantive feedback and helped further refine the NVivo list of 17 factors from the KIIs. The PI and KIIs simplified the original list to the Top Ten Factors for Successful Transition (Table 6). In **Phase 3** the Stakeholder Action Planning Session prioritization exercise emphasized the three most crucial factors for successful transition as: 1) adequate and affordable medical insurance coverage; 2) individualized physical/mental healthcare plan, and 3) ongoing provider support for the transition process (medical and social worker/bridge counselor), respectively.

In addition, the triangulation of the multiple data sources corroborated reliability of the recommendations and promoted the system model and the research findings as a method to improve health outcomes for individuals with HIV, an outcome that has promise to facilitate a decline in transmission of the infection to others in this highly susceptible population.

Table 6: Top Ten Factors for Successful Transition

Key Factors		Summary
#1	Adequate and affordable medical insurance coverage	Ranked as the top priority for successful transition, participants remarked that without adequate and affordable medical insurance they could not access care and their physical and mental health depends on access to quality care.
# 2	Individualized physical/mental healthcare plans	Health plans must be holistic, integrated, and individualized to assure smooth transition. Transition readiness factors vary from one person to the next.
# 3	Ongoing provider support throughout the transition process (medical and social worker/bridge counselor)	A team approach from the provider team is crucial for the various stages of transition. From early in adolescence to the final stages of transition the young person and their family need ongoing support.

# 4	Family/Caregiver Support	The involvement of the family/ caregiver is vital to the young HIV-infected individual. Families also need support to enable them to help maintain life balance for their HIV-infected youth. Stable emotional and physical support for family and youth is critical for successful transition.
# 5	Patient-centered medical home with access to “wrap-around” services	Wrap around services that link HIV-infected individuals to human services programs, bridge counselors, dental, vision, and mental health services assure patients basic needs are met and greatly enhance outcomes for the patients.
# 6	Career guidance and planning for transitioning youth	The AAP COPA recommendations stress providers should ensure that not only is the youth’s healthcare adequate but that educational, vocational, and social service needs are discussed and addressed. Parents and young adults interviewed concurred.
# 7	Strong self-advocacy (self-efficacy)	Interviewees stressed the need for self-efficacy, confidence, and ability to exert control over one’s motivation, behavior, and social environment to navigate transition. The earlier this skill is cultivated, the more likely the transition is successful.
# 8	Must address stigma issues (among providers and community)	Each individual interviewed described ongoing issues and concerns with stigma surrounding HIV, both among providers and the greater community. All believed more effort to decrease stigma, especially among non-HIV care providers is needed.
# 9	Age-appropriate educational support (childhood to adulthood)	Education for the pediatric HIV-infected patient and family should start early and reinforce age-appropriate messages as youth transition. From coloring books to condoms, accurate information is vital to self-efficacy.
#10	Technology support and access to electronic health records (EHR)	Various forms of technological support were discussed: EHRs, text reminders, telemedicine links, educational support. Interviewees expressed their perceived benefits to improving compliance.

Key Factor 1: Adequate and affordable medical insurance coverage

SEM Policy Level

Ranked as the top priority for successful transition, participants remarked that without adequate and affordable medical insurance they could not access care and that their physical and mental health depends on access to quality care. One parent/caregiver emotionally shared her thoughts:

It is very stressful, extremely stressful, to not be able to pay bills, I would cancel medical appointments, I could not pay the co-pay; I would have to decide... Do we all get our meds, go to the doctor, pay the rent, or pay the electric bill. We want to be self-sufficient but I would say the financial is a big reason for failure and depression among those with HIV.

Many participants expressed concerns regarding the dilemma of affordable care and many comments were made about the Affordable Care Act (ACA) Market Place insurance plans: “Obamacare has helped, but it is not easy to understand it, or pay for it. The plans will not cover HIV medicines or healthcare. It is complex and you need someone to help navigate the process or you get lost fast.” Programs such as the North Carolina AIDS Drug Assistance Program (ADAP) were described as “valuable support for those that do not have insurance plans” and many interviewees expressed concern over signing up for Market Place plans that could jeopardize ADAP, “I’m afraid if I get insurance I’ll lose ADAP for my medicines, the plans have high copays.” The combined state- and federal- ADAP program provides low-income (i.e., up to 300% of the poverty level) residents with coverage for essential medications for HIV, related conditions, and other co-morbidities. ADAP also covers some prevention and treatment of related opportunistic infections.¹⁰⁰ ADAP combined with the federal HRSA Ryan White HIV free clinics remain the only source of care for many individuals with HIV.

Even those with employer or private insurance coverage options described significant issues. One mother of two HIV-positive children stated, “I have 6 doctors, I cannot go to one if I do not have money for the co-pay. The underlying problem is not having the financial money bag. I have Blue Cross Blue Shield through my employer, but the premiums are expensive and I cannot afford the co-pays.” Also, an HIV + young man expressed his reluctance to seek employer coverage due to the fear of having to reveal his status. The fear of stigma carries a heavy weight even with decisions regarding insurance coverage.

Although family insurance plans can now be extended until age 26, private plans are expensive and co-pays are high. As the young adults “age-out” of NC Medicaid (age 19) or family insurance coverage (age 26), continued gaps in insurance coverage and Medicaid will be barriers for the majority of young HIV-infected individuals.

Recommendations:

Conversation with state and federal level policy makers should be organized with HIV Care stakeholders. The primary focus is consideration of how to best align the various federal, state, and private market HIV health plans (Ryan White funds, ADAP, Market place plans, Medicaid, social service programs, private or employee insurance plans, co-pays, and medication plans). Coordination of plans could align and maximize resources to achieve improved outcomes in a more cost-effective manner. A modified HIV insurance plan may best be described as a “patchwork” system of coordinated options, which customize plans for the individual and family needs. Also, to circumnavigate the system, trained social workers and bridge counselors can assist all HIV-infected individuals in selection of plans that best meet their needs. In the case of HIV, treatment is prevention and reduction in new infections.

Key Factor 2: Individualized physical and mental healthcare plans

SEM Healthcare Level

“I am not HIV; I am a person” retorted one 21-year-old HIV-infected young woman. The KII responses reiterated that the health provider’s care plans must be holistic, integrated, and individualized to assure smooth transition. Transition readiness factors vary from one person to the next, and the interviewee’s descriptions of when transition should occur also varied. “Some are ready at 14-15 to start talking about transition, but I would say most aren’t really ready to transition until they are in their mid-20s. It really just depends on the individual. There are no cookie cutter plans.” As stated by one young HIV-infected adult, “There’s a lot of growing up goes on between 16 and 25.”

KIIs also expressed the belief that the patient (and family, when appropriate) must be involved in the mutual development of a written plan that is understandable to the young person and his or her family. Plain language documents were recommended, materials in which people can find what they need,

understand what they find, and act appropriately on the information to increase self-efficacy.¹⁰¹ Including health literacy experts in the development of the plan is suggested. Electronic access to the care plan was also noted by KI interviewees.

The perception of the family's desire to be involved was reinforced by the AAP COPA recommendations. These recommendations emphasized that a formal process of transition from youth to adult healthcare led by the referring provider should include written policies to define the process and that the plan should be shared with all pediatric/adolescent or family medicine providers, staff, and patients and their families with appropriate staff training. The transition plan should also establish a system to identify and track youth as they progress through the transition process.¹⁰²

KI interviewees also stressed a need for the entire team to contribute to the plan (mental health, social worker, bridge counselor, medical provider, etc.). Many of the interviewees stressed that providers need to assure that an individual's physical and mental healthcare is integrated. Personal experiences were shared that reflected a gross lack of coordinated care between mental health and physical needs.

"Providers need to increase their awareness between physical/mental health services. You can't treat a person's body and not treat their mind. HIV carries a lot of mental burdens too," stated one KI interviewee. Co-morbidities such as asthma, diabetes, behavioral disorders, substance abuse, and other health conditions were part of the real life issues described and therefore must be part of an integrated care plan. Although there are some predictable hurdles and certain benchmarks can be consistently applied for HIV-infected youth as they transition, one-size does not fit all and individualized care is required to assure successful transition.

Recommendations:

The AAP COPA recommendations emphasized that a formal process of transition from youth to adult healthcare should be led by the referring provider and that providers should include equitable participation of the patients and their families in development of the transition plan. Written policies to define the process and assurances should be developed. Additionally, the plan should encourage input from the entire team (mental health, social worker, bridge counselor, medical provider, etc.). All health

providers involved in the process should have access to the plan. The transition plan should also establish a system to identify and track youth as they progress through the transition process to assure key benchmarks are met. Electronic access to the care plan was also noted by KI interviewees.

Other factors to consider include possible co-morbidities, and mental health needs were a recurring theme from the KIs and should be addressed in the plan. Plain language documents are recommended and health literacy experts should be included in development of the plan to assure patients and families fully comprehend the plan. Finally, it is recommended that evaluation or research should be conducted to assess the level of adherence and utilization of the AAP COPA recommendations among North Carolina HIV pediatric providers.

Key Factor 3: Ongoing provider support throughout the transition process (medical and social worker or bridge counselors)

SEM Healthcare Level

An integrated approach from the provider team is crucial for the various stages of transition. From early in adolescence to the final stages of transition the young person and their family need continued support. Sincere appreciation was voiced by many of the perinatally-infected HIV young adults for the relationships that had been established between them, their providers, and their social workers. Stories of assistance during dire financial times, difficulty with transportation to medical appointments, eye glasses, educational conferences, insurance plans, assistance with scholarships and other basic needs were described. One young woman humorously reported that her social worker, whom she called by first name, “[name] has been my strongest supporter even when I didn't want her to be there; she has been there for me and helped me to keep things in line. I would not be in college today if it weren't for her.” The move to more independence can be challenging for these young HIV-infected individuals and their families but ongoing support is invaluable.

Many perinatally infected young adults are missing one or both of their parents. One young man who recently transitioned to adult care shared his thoughts:

Having someone to help plan for when to begin the transition, explaining the different doctor appointments, seeing if someone could walk you over there before you have to go on your own so you do not get lost the first day and jeopardize the whole deal, having at least that one person follow up and ask you how was it? That really helps.

AAP COPA recommends that the referring healthcare team should be available during the transition and to the adult healthcare provider to serve as a resource during the immediate post-transfer period.¹⁰²

Another important role the social workers play for the HIV–infected youth is to educate and explain the difficult navigation into the adult sexual world. Transition of course corresponds with adolescence, a phase that is typified by self-exploration and risk-taking behaviors such as sexual debut, short-term consecutive partners, and experimentation with alcohol and drugs.¹⁻³ HIV-infected youth must learn to navigate a complex health regime, legal issues, and the social stigma that is associated with HIV to protect themselves and to avoid transmission of the disease to others. For those adolescents who are already HIV-infected there must be a highly integrated system of care to protect their health and the health of the population they are part of. The PHIV young adults and their caregivers expressed gratitude for the role the social worker plays in facilitating sexual education and in assuring that the HIV-infected individual has adequate information to make informed decisions.

The grandmother of one of the young HIV-infected youth expressed appreciation for the willingness of the social worker to “coach my grandson on how to communicate his HIV status with his partners.” When she first became suspicious that her grandson was having sex, she talked to the social worker and asked if the social worker would talk to him. “It’s just not that easy to get your kid to listen to his grandmother about sex. But he was ok with her [the social worker] talking to him.” The grandmother was thankful to have someone to help.

Sadly, none of the behaviorally-infected HIV-infected (BHIV) young adults shared a similar story of support from their health team. Although they stated their provider did talk with them, the level of wrap-around services was significantly less and there was very limited support in the clinics for any type of service other than the basic medical care for HIV and some medication assistance. Several of the BHIV youth started their treatment in adult care and did not have the support of the pediatric outreach social

workers. This is a significant gap for the behaviorally–infected population. Frequently, they described unmet basic needs, confusion regarding resource links, housing issues, and most were not enrolled in post-secondary education and did not even finish high school. The BHIV youth were significantly less informed about various resources available to them. One young man in Raleigh stated the following:

I would say everyone needs some kind of outside help, outside of family because being too close can interfere with how you deal with stuff. Outside sources that would be removed from the drama and the situation enough so that they could solely focus on the health issues and the business of it all, they could understand and just help me along. That would help.

Bridge Counselors or social worker assistance would be a significant enhancement to the care of BHIV youth and young adults to assure improved outcomes and decrease transmission.

Recommendations:

The AAP COPA recommends that the referring healthcare team should be available during the transition and to the adult healthcare provider to serve as a resource during the immediate post-transfer period. For the young BHIV youth there are significant gaps in social worker and bridge counseling support. Either service would be a significant enhancement to their care and could assist them through the myriad of decisions, insurance planning, and service links. To enhance improved outcomes and decrease HIV transmission, an acuity ranking scale should be used to allocate appropriate staffing for young HIV-infected individuals by facilitating appropriate linkage to social workers or bridge counselors based upon the young person's needs.

An acuity ranking scale provides a much needed tool to identify particular young HIV-infected individuals whose life circumstances indicate the need for social worker or bridge counselor caseworker services. Such linkage will promote improved outcomes and decrease HIV transmission. The *Acuity Ranking Scale for HIV Case Management Staffing Allocation* instrument (See Appendix 4) was developed by Wake County Public Health and serves to assess and prioritize needed services. Though acuity staffing is seldom used in public health settings it is an appropriate staffing model, “acuity can be defined as the measurement of the intensity of...care required by a patient,”¹⁰³ or client. An acuity-based staffing model adjusts the staff to client/patient ratio according to the client/patient's needs. Client needs

may range from minimal assistance to needing a dedicated caseworker on a daily basis.¹⁰⁴ The instrument helps with addressing identified barriers to improving health outcomes and protecting population health by recognizing factors such as social determinants, physical and mental health status, and compliance with care regimes. Because the scale provides a tool to target individuals who have acute needs requiring considerable staffing attention, the Wake County Public Health Division is utilizing the scale to more efficiently allocate staffing resources. The acuity scale was designed specifically for HIV positive individuals in order to address the particular health and social determinants. Tracking mechanisms for the transition process should be established to identify and track youth through the transition process to assure that key benchmarks are met. The need for electronic access to the care plan was also noted by KI interviewees. Federal mandates should be in place in most care settings within the next two years.

Key Factor 4: Family and caregiver support

SEM Relational Level

The involvement of the family, a caregiver, or a close network of friends is vital to the young HIV-infected individual. For the HIV-infected youth to have stable emotional and physical health backing from family and friends factored heavily into the prioritized factors ranked by key informants. Many HIV-infected youth are not residing in their birth homes, either living with grandparents, other relatives, or foster care. Additionally, the potential for psychosocial stressors which include parental loss, placement in foster care, poverty, homelessness, unemployment, discrimination, and abuse is elevated among adolescents with HIV.¹⁰⁵

The KI interviewees all made reference to the need for familial support to navigate the challenges of HIV care transition. Comments such as, “We all need that ongoing support of family or someone that will be there with you. If you don’t have that security, it is easy to fall apart.” Many expressed that they believed that their family actually grew closer because of the HIV, “It’s kinda like you all share this battle and everyone knows we must depend on each other.” One family composed of two teens and their grandmother described the obstacles they had navigated: death of the mother, imprisonment of the father, stigma, financial obstacles, and illnesses. Nevertheless, the positive deviance that had emerged for them

was a strong family core of support and perseverance, “I think we are closer because of all this.” As mentioned earlier, some individuals or groups whose uncommon behaviors and strategies enable them to find better solutions to problems than their peers, while having access to the same resources and facing similar or worse challenges evolve a type of positive deviance.¹⁰⁶

Family involvement is recommended for support during the transition planning. Again, the AAP COPA recommendations stressed the need for the provider to include the youth and the family in a jointly created and individualized transition plan.¹⁰²

Recommendations:

Provider support and education for the family/caregivers of HIV-infected youth is part of an integrated care plan. Family involvement in the transition planning process should also address the potential needs of the family and enable the family/caregiver to focus attention on the needs of the youth. Social worker support for the difficult conversations and issues reinforces the skill set needed by the parents.

Additionally, there is high potential for psychosocial stressors in the HIV family structure. Mental health support should not be overlooked for the family members.

Key Factor 5: Patient-centered medical home (PCMH) with access to “wrap-around” services

SEM Policy and Healthcare Provider Levels

Although, research participants did not use the technical terminology associated with a PCMH, they intuitively described the concept repeatedly:

They [providers] need to treat my child as a whole person. Folks [...] with HIV are almost always dealing with more than one health condition and it takes more than just drawing our blood work, telling us to practice safe sex, and writing a prescription for our meds. We have lots of conditions: diabetes, high BP, nutrition, dental, mental health problems and other issues.

To understand technically what they were describing as the key need of a “good medical home” that can link them to needed “other services like mental health or social services help,” one must understand what a PCMH is intended to do. The insight of the interviewees is clearly reflected in the literature and the AAP COPA recommendations.

The Agency for Healthcare Research and Quality (AHRQ) describes PCMHs as follows:

“Patients who have complex health needs typically require both medical and social services and support from a wide variety of providers and caregivers.” Strategies are needed to help primary care practices perform as effective medical homes and coordinate services for patients with complex care needs.¹⁰⁷

One can understand the rationale for a PCMH that has HIV-specific expertise embedded in the clinical care. HIV is one of the more complex chronic health conditions. This is especially applicable for transitioning HIV-infected youth. Because HIV’s context socially, the ongoing gaps both in HIV care and services favorably position the existing Ryan White HIV/AIDS programs as prime candidates to evolve into the more integrated HIV PCMHs. Already, policy makers across the country are being encouraged to consider transitioning existing Ryan White Programs toward the PCMH model and to build on the established success of the 1990’s Ryan White Care Act. Early clinical adopters of the PCMH model have already shown evidence of improved quality of HIV care and are achieving better clinical outcomes. The PCMH is a highly recommended model for HIV clinical care.¹⁰⁸⁻¹¹¹

Comments such as the following from one caregiver reflect the complexity of HIV care from the patient’s perspective:

I have 6 doctors. I’m not sure any of my doctors ever even communicate; seems like they don’t. I get all these referrals, but I cannot go to one if I do not have money for the co-pay. The underlying problem is not having the financial money bag. Even with my Blue Cross Blue Shield I cannot afford all the co-pays.

Currently, North Carolina is one of the many states in the midst of healthcare and Medicaid reform. Options for the use of Ryan White federal funds, ADAP, new ACA Market Place plans, state Medicaid dollars, and other state funding should be evaluated. Some progress has been made since the beginning of this research. The NC ADAP has recently implemented the (ICAP), Insurance Copayment Assistance Program to coordinate with Qualified Health Plans to purchase medications on the Federal Marketplace (Healthcare.gov) to pay all out of pocket costs for any medications covered by the primary qualified health plan. This effort has been led by the NC Department of Health Communicable Disease Branch and others such as the HIV Roundtable Policy group.¹⁰⁰

Another promising effort in North Carolina's Triangle region that is currently underway is the effort of the Wake County Human Services Ryan White HIV Clinic to accommodate the PCMH model and begin accepting marketplace plans. Historically, the Clinic's team has provided comprehensive HIV services. To enable continued high quality care for Wake County's HIV clients and to improve fiscal responsibility in an evolving healthcare market, the County HIV Clinic has submitted a proposal to Blue Cross Blue Shield of North Carolina to be recognized as a primary care PCMH. This transformation is projected to stage the clinic as more attractive to the new Accountable Care Organizations (ACOs) or Managed Care Organizations (MCOs) that are proposed to evolve in the NC provider PCMH environment.

Despite having developed comprehensive care coordination and case management packages of services that are associated with the PCMH business model, the Wake County Clinic has not been recognized as a PCMH because it did not fit the formal primary medical home definition established by the insurance market prior to ACA changes. The proposed Wake County model is intended to enhance and expand current HIV service offerings and assure appropriate credentialing of providers to be more in line with PCMH requirements. This natural evolution of the Clinic's business plan is well aligned with their current mission of providing high quality wrap-around care for HIV clients.

As more HIV patients enroll in the Marketplace insurance plans, HIV clients have expressed a desire to continue in clinics they are familiar with and that have the expertise and wrap-around services suited to address their special needs. Clinics built on this model will attempt to continue services and become more attractive to the new ACO and MCO plans that are proposed to be developed in NC. The evolving healthcare reform environment should address the needs of HIV providers. Providers should be able to serve the new Marketplace clients and avoid leaving transitioning HIV-infected youth with limitations in their choice for primary providers that may lack expertise in HIV care.

Increasingly, state Medicaid programs are adopting the PCMH care model to improve access and quality to care for other chronic health conditions.¹⁰⁸ North Carolina policy stakeholders should consider several important areas for action and research with regard to development of the HIV PCMHs.

Recommendations:

Policy options must be encouraged for the transition of Ryan White (RW) services and federal funds to adapt to the new ACA Marketplace and the patient centered medical home (PCMH) models. A major consideration is how to best utilize and align the various federal, state, and private market HIV health plans (RW funds, ADAP, ACA Marketplace plans, Medicaid, social service programs, private or employee insurance plans, co-pays, and medication plans).

Clinics that limit care to only chronic infectious disease management should be exploring how the clinic can better align with other service agencies to assure the availability of wrap-around services for their patients. Also, training for the existing RW clinics to encourage clinic structure and business plans that accommodate the new requirements should be part of the state and federal planning. This is especially applicable for clinics that serve transitioning HIV-infected youth and young adults. The François-Xavier Bagnoud Center within the Rutgers School of Nursing and the University of California, San Francisco, has previously collaborated with multiple partners to form a resource link for RW PCMH's. The program was funded as a national training and technical assistance center for three years. The intent was to build upon existing strengths of RW Program grantees to strengthen primary care for those living with HIV/AIDS.¹¹² Although the funding ended in 2014, the resources and information are still online and were updated in 2015. Policy makers in North Carolina should consider several important areas for action and research with regard to development of the HIV PCMHs.

Key Factor 6: Career guidance and planning for transitioning youth

SEM Healthcare Provider and School Levels

There was consensus from the KI interviews, the literature, and the AAP COPA recommendations regarding the need for career guidance and planning for transitioning youth. The recommendations stress providers should ensure that not only is the youth's healthcare adequate but that educational, vocational, and, social service needs are discussed and addressed. The parents and young adults interviewed here concurred.

The PHIV youth interviewed had received active engagement from the Pediatric Outreach Social Workers associated with the pediatric HIV clinics. Strong evidence of long-range planning was apparent from interviews with the HIV-infected young adults and the caregivers. “My social worker has been a real life-saver; I doubt I would be in college if it weren’t for her help. As a matter of fact, I would not even have glasses right now if she had not helped me.” When the PI asked the PHIV participants questions regarding their social worker’s assistance with education, vocation, job training, or planning for the future each one enthusiastically reported they were encouraged from a young age to plan. “Seems like that was one of our common talks; we talked about it all the time.” The role of the social workers in supporting the youth and their families in vocational and educational planning had benefited all PHIV adolescents and young adults.

AAP COPA values the educational and vocational factor enough to stress the need to ensure that in addition to the youth’s healthcare needs, educational, vocational, and social service needs must be discussed and addressed.¹⁰² Educational attainment has long been recognized as a social determinant of health; therefore, there is no surprise that congruency exists between the statements of the KI interviewees, the literature, and AAP COPA recommendations.¹¹³⁻¹¹⁵ Educational attainment also contributes to improved self-efficacy, income level, and life satisfaction. One young interviewee stated, “I am really proud of myself for finishing my education. I am the first in my family and it feels good.”

There are scholarships available that can help HIV/AIDS individuals with money and resources that they may need in order to pursue their college career. Charitable organizations and private endowments scholarships typically provide funding.¹¹⁶ Some of the young PHIV KI interviewees reported receiving scholarships related to their HIV/AIDS status.

Unfortunately, as mentioned earlier in this research, none of the BHIV young adults shared a similar story of support for social needs, educational, vocational, or career attainment. The level of support and information sharing for the BHIV youths was negligible from their reports in the KI interviews. This is another significant gap for the behaviorally-infected. Participants frequently described unmet basic needs, confusion regarding resource links, and lack of high school diploma and post-

secondary education. When questioned by the PI, the BHIV youths' replies ranged from, "I'm thinking about going back for my GED, but just kinda getting by the best I can now," to "I would like to sign up for the chef's school, but just not sure where to start." Bridge Counselors and social workers could aid improvements in population of youth transitioning to adulthood.

Recommendations:

Career and vocational counseling should be a component of the overall case management for all HIV-infected youths ages 15-25. This is yet another valuable function the social workers and bridge counselors can actively fulfill in working with the youth. Linkage to the educational and vocational resources can be a predictor of future health outcomes and the financial burden of healthcare. Funding sources could incorporate career/vocational mentoring into the responsibilities of HIV social workers, and outcome measures could be monitored in the various HIV funding sources. Also, although most public schools would be unaware of the HIV status of students, the students can be coached by health providers and social workers to seek the guidance and resources that are available at their schools.

Fortunately, there are scholarships available that can help HIV/AIDS individuals with money and resources that they may need in order to pursue their college career. Charitable organizations and private endowment scholarships typically provide funding. Also, most colleges and universities have special scholarships for people living with HIV/AIDS as well as other income-based scholarships.¹¹⁶ When research has repeatedly shown educational level as an indicator of improved health outcomes we cannot afford to overlook this key factor.

Key Factor 7: Strong self-advocacy (self-efficacy)

SEM Individual Level

At the heart of readiness for transition to adult care is strong self-efficacy for the transitioning youth. Interviewees stressed the need for self-efficacy, confidence, and the ability to exert control over one's motivation, behavior, and social environment to navigate transition. Balancing support from family, caregivers, and providers to assure appropriate self-management was noted as a key factor. For the young person living with HIV/AIDS, self-efficacy and their own ability to manage the transition to adulthood

and adult care is important for multiple reasons including the following: medication compliance, legal notification to sexual partners of HIV status, use of condoms for protection of self and others, assuming independence in medical and insurance management, and adequate financial and social supports, to name a few. The earlier self-efficacy skills are cultivated, the more likely the transition is successful.

Many professionals caring for HIV patients agree that some of the stronger predictors of success are individual factors. Again, Barrett et al.²⁴ indicated that the unmeasured individual factors such as relationship with support staff and self-efficacy may have an even greater impact on successful transition than many other factors. Assessment of self-efficacy is recommended for transition readiness, but there are numerous considerations for health practices that intend to assess self-efficacy. Behavioral specificity for HIV, assurance of formative question research and instructions that are aligned with health literacy levels should be considered. Also, there are no all-purpose approaches to the measurement of self-efficacy. The self-efficacy measures must be tailored to specific functional domains, and with HIV, to specific populations.¹¹⁷⁻¹²²

KI interviewees did discuss the importance of self-efficacy and relationship balance in numerous ways. Interviewees revealed findings similar to those in early research literature by Hauser and Dorn on transitioning youth with chronic illness such as sickle cell disease. For the transitioning youth with SCD, the three major concerns were 1) leaving providers they are familiar and comfortable with, 2) having to see a doctor who is unfamiliar with their needs, and 3) trepidations about breaking from parent/caregiver support.^{25,70,77,123} Young people living with HIV, however, noted the most significant anxiety for independence were concerns regarding adequate financial resources and medical insurance coverage, “Financial burdens are a big reason for worry, not having medical insurance, not understanding how to sign up and keep insurance, really makes me worry.” Several participants voiced similar comments and noted that to be independent they needed to believe this part of life could be managed. Also, ease of access to portable healthcare records was noted by some, including one who remarked, “If I can see my

med list, know the meds have been ordered, know the results of my lab tests, and some of my other records, I feel more in control. Like I know where I stand.”

During the closing activity for the SAP discussion the group participated in a “Connection Circle Exercise.” The purpose of the connection circle, which is considered a promising practice,⁹⁹ is “to see important variables and connections between variables.” One participant drew a simple but elegant “connection circle” composed of five fundamental connections: self-worth, ability to meet material needs/have needs met, become and stay goal-oriented, achieve mastery of a chosen domain in life, and have a “shepherd” or advocate to help with the process.

Not having a home social worker to help was also reported as an identified concern. The social workers can alleviate many of the logistical health concerns and serve as a bridge to independence. One 20-year-old KI interviewee said, “Sometimes you just need to talk to someone other than family, someone you can trust and someone that is up on all this HIV stuff. There’s a lot to keep up with, but I think I am ready to stand on my own if I can know I have someone there. You know - someone to call if I need them.” Transition readiness improves and anxiety decreases as self-efficacy increases for both the youth and the caregivers.

Incorporating a self-efficacy measure into the readiness assessment could have merit. There are assessment tools for self-efficacy and HIV transition readiness. The “Transition Readiness Questionnaire” used by Weiner et al.⁶⁸ assesses obstacles to a successful transition including identification of an adult care provider, access to medical insurance, and knowledge of disease status and medications. However, most KI interviewees were not aware of having received a similar questionnaire. Other simple measures mentioned include access to electronic records, text reminders, disease process education, awareness of various resource links, housing support, and linkage to peer and family supports.

Recommendations:

Assure the AAP COPA recommendations are utilized to prepare youth for transition early in transition. Conduct readiness assessments that identify strengths, gaps, and inform education plans for youth and parent/caregivers. When possible, continue link to outreach social workers to address the

logistical and emotional stability for transition. Encouragement of education as mentioned earlier can aid self-efficacy. Also, assurance of appropriate access to one's own electronic health records and the awareness of how to navigate those records and resources facilitate an improved feeling of independence.

Key Factor 8: Stigma Issues must be addressed (among providers and community)

SEM Community and Societal Levels

Each individual interviewed described ongoing issues and concerns with stigma that surrounds HIV, both among health providers and the greater community. All believed more effort to decrease stigma, especially among non-HIV healthcare providers, is needed. HIV-infected youth must learn to navigate a complex health regime sometimes traveling great distances to avoid the social stigma in their hometowns. They also voiced not disclosing appropriately to health providers and others to avoid the fear of being stigmatized. Addressing stigma that is associated with HIV requires more attention to protect the youth and to avoid transmission of the disease to others.

Although HIV can be compared to many other chronic diseases that require age-appropriate transitional planning, stigma is a major factor for parents, children, and young adults. Parents and youth describe great difficulty with disclosure of their HIV status.^{15,28,43,55} Teens and young adults require individualization of care that can address their unique sexual experience, relationships with peers, and often a casual attitude toward sex.

Stories from KI interviewees revealed deep emotional scars. One grandmother described a disappointing response from a local doctor. Her grandson, who had been a star high school athlete, in his junior year was told by his local doctor that the young athlete was required to notify coaches of his HIV status if he intended to play sports his senior year. Instead of following the doctor's directive, the grandson dropped out of sports. Although the information from the doctor was obviously wrong, the 17 year-old was not able to manage the hurdle. Sadly, at the time of the interview, his grandmother reported, her grandson had begun "hanging out with the *wrong kids* and failing some of his classes. He had always done fine with school 'til then."

In another situation, a caregiver described being, in her words, “outed” by her hospital nurse and fellow church member:

I was in the hospital [hometown] and was having a problem with edema, fluid around my heart. She [nurse] came into my room and I recognized her right away from our church ... and she looked at me and she didn't even open her mouth... she just kept looking at me. A little voice in my head said, Oh no, you are in trouble... She is going to tell... I don't think she meant to tell the whole church, but you know how that goes. She told one person I guess and the one person she told was the wrong person to tell. Next thing I knew my whole church knew.

Yet another story reflected the deep seated fear of stigma in a workplace. “Right now I could have insurance through my workplace, but I know we are a self-insured group. I am concerned that my meds and care will be revealed at work, so I am staying on my mom's plan as long as possible.” Even though the mother's plan was more expensive for him his risk avoidance of stigmatization was strong.

A different type of worry or concern surfaced as one recent college graduate described her fear of breaking up with her boyfriend of 12 months because, “I know he is likely to tell everyone about my status. I feel very intimidated because he knows my secret. If we break off, he will use it.” Her very tangible fear of how to move on was evident. Concerns regarding marriage and having a family also surfaced for several young adults. None of the young adults interviewed were in stable relationships at the time of the interviews.

Emotional health and hope for the future is intimately linked to physical health. Stigma presents many challenges for those in need of services and healthcare, and can significantly affect whether infected individuals adhere to treatment, follow disclosure requirements, and keep stability with their mental health.^{29,124} Providers and the health team can play a significant role in coaching on techniques for disclosure. Skills sets that are accurate and based on facts are necessary to avoid transmission, to improve self-efficacy, and to increase resilience in the HIV-infected youth.

Recommendations:

Enhance self-efficacy training by HIV providers to improve the young person's communication skills with friends and providers. Both providers and HIV-infected individuals need to gain skills in appropriately addressing concerns of HIPAA violation. More pro-active educational outreach is needed

for medical providers in rural communities. Finally, legal action is necessary for known violations of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Recommendations for role-playing “disclosure scenarios” were described as beneficial by the youth that had participated in such training. It is recommended that all young people living with HIV/AIDS have opportunity to receive similar training for disclosure. Also, in-depth and accurate disease process education and medication training can enhance self-efficacy. When available peer navigators can act as mentors and role models to transitioning youth who are learning to cope with the daily challenges of living with HIV. Peer navigators are generally knowledgeable about community resources, including educational, social and emotional support services, which are available to HIV-infected individuals. North Carolina has used peer navigators successfully in some settings and it is likely this would be a positive method to augment the social worker’s resources.

Key Factor 9: Age-appropriate educational support (childhood to adulthood)

SEM Healthcare and Educational Levels

Education for the pediatric HIV-infected patient should start early and reinforce age-appropriate messages as youth transition. From coloring books to condoms accurate information is vital to self-efficacy. KI interviewees described why some lessons must be heard multiple times and in multiple ways. Some of the PHIV youth said they still benefit from camps and conferences that they attended over a decade ago.

There was again a marked difference in the reports from the PHIV youth and the BHIV youth. Outreach social workers and in-house staff in the pediatric practices were described as having specific plans although none of the participants were aware of an actual written plan for their educational plan per the AAP COPA recommendations. However, from the PHIV individuals’ descriptions it was clear the educational process did occur and topics such as disclosure, medical treatment, insurance; ADAP, medication adherence, and career planning were all included.

One KI interviewee reported, “When I was younger it was like coloring and stuff like that, and as I got older it was just more factual presentation. It was really great, quite age-appropriate and helpful.”

Also, several described special camps and conferences as they grew into adolescence and their teen years. All voiced benefits from these special events and even listed the events as a positive experience. One KI interviewee related the story of a memorable experience, “My trip to a conference in Puerto Rico was amazing; I realized how much better our situation is than most other places. The conference was really helpful in teaching me how to open up to other people.”

The BHIV participants had a more varied and random experience with their HIV education. Some described positive educational experiences with their physicians, “My doctor takes a good amount of time and tries to cover a lot of stuff I need.” Nevertheless, the majority of the BHIV youths described their educational experience as self-taught from the Internet or from peers and often “older men.” One participant, 21 years of age, stated it this way:

I would like to just get away from the old men for information. I don't know what the deal is about the old men and me that is just offensive. I guess if we were more the same age... But there was this one man that was really nice; he was like, “if you ever need help with your medicine, feel free to ask me your question.” Or, “If you're out, and you need to use some of mine, if it happens to be the same [you can use mine.]” And I hooked up with this other guy and I prefer to use condoms and he does not; so you run into all of these kinds of issues in some of these places.

Another the KI stated his frustration over the many issues he has, “getting the information I need.” He complained that when he needs to speak to his doctor, she is “never available.” In his words, “Every day I am really working to try to make my healthcare plan come to fruition, but it is a lot of BS, red tape, and running around. And it's like, damn, I can't even get my doctor and I can't even talk to them about my problem.”

Insurance and ADAP information was also randomly shared with the young HIV patients. Some of the BHIV youths stated that their providers addressed the issue of Marketplace insurance and some said their providers did not. Topics such as the legality of status disclosure and medication adherence were consistently addressed by the medical providers. No career or vocational education plan was made available to any of the BHIV youths.

Recommendations:

Per the AAP COPA recommendations, the provider, the youth, and the family should jointly create an individualized age-appropriate written transition plan well in anticipation of transition. The written transition plan should include creation of a portable medical summary and/or electronic health record (EHR) and an emergency care plan. All providers of care for young HIV-infected individuals, ages 16-25, should assure at minimum education on the following mandatory topics:

- HIV status disclosure methods and related legal requirements
- Safe sexual practices
- Associated medical treatment plans
- Appropriate insurance coverage
- Information related to ADAP and other resources
- Medication adherence tools
- Career planning

It is also recommended that quality control measures be built into the various funding sources for HIV care to assure the above mentioned minimal education requirements.

Key Factor 10: Technology support and access to electronic health records

SEM Policy and Healthcare Levels

Various forms of supportive technologies were discussed by KI interviewees including personal health records (PHRs) or electronic health records (EHRs), text reminders, telemedicine links, and tech-based educational support. The interviewees expressed their perceived benefits and challenges to improving compliance when tech options are available.

PHRs or EHRs are a new option for HIV patients. Many of the KI interviewees were just beginning to experience how they may benefit from this new resource, and interviewees said they want and need this new electronic tool to facilitate management of their health information. However, until some of the gaps are bridged, it is unlikely that PHRs will be widely utilized by young people living with HIV/AIDS. Some barriers to adoption include provider cost, concerns that information is not fully protected, and lack of convenient access for some families. One grandmother of a teen with HIV said, “I know the doctor has a lot of my grandson’s records on the internet but we don’t have a computer and I’m

not sure I would use it if we did; just not sure how to use computers yet.” As these concerns are addressed, the likelihood of increased usage is probable. Assuring that patient records are portable and user friendly, both in content and format, will likely make PHR/EHRs an invaluable resource for transitioning youth.¹²⁵

The following reveals the perspective of several of the participants:

I have access, but sometimes I have no clue of what the numbers mean. What does my *creatinine* mean? Am I *anemic*? Are my numbers good or bad? What should the range be? Who would even think that the medical info could be so overwhelming? Providers must educate their patients on what it means, make it understandable. Make the records clear.

Most believe that the ACA’s “Meaningful Use” requirement for patient access to their EHRs will improve caregivers’ decisions and patients’ outcomes. One young adult comment reinforced this idea:

You know I get the blood work done regularly and it would be kind of easy to make a comparison from one period to the other. You know, a trend chart, which would make that part a little bit easier to understand. I think that would definitely be beneficial because I could track it and make sure that if there were any variation in it I would notice it. I would know if I am improving or declining.

Emerging healthcare technology is beginning to increase patient engagement in their healthcare. Early studies have already shown evidence those HIV patients who utilize the EHRs more frequently have steady improvement in adherence as monthly frequency of use increased. By allowing increased communication with providers, refilling prescriptions, scheduling appointments, and viewing portions of their medical records, outcomes improved.¹²⁶

Some also noted that it would be helpful to take advantage of the new telemedicine options; ideas such as decreasing in-office visits and replacing some of the follow-up visits with teleconferences would be a time saver. Several of those interviewed travel one to two hours for their medical appointments and, naturally, there is significant cost associated with travel, parking, and having time away from work. One young woman even commented about the inconvenience of paying for parking at her visits to her doctor, “You would think that they would not charge you even to park and come into our doctor visits; it’s expensive enough to get back and forth without having to pay parking fees.” Most said they would not want to totally replace the face-to-face visits with their doctors but would welcome intermittent

teleconference appointments. Lastly, simple text reminders for appointments, medication refill reminders, lab results, and other secure messaging were welcomed options for quick and uncomplicated messages mentioned by KI interviewees.

An additional incentive to hasten the patient “user friendly” EHRs is the 2015 Stage 2 of Affordable Care Act’s Meaningful Use requirements which mandate patient access objectives.¹²⁷ Below are some examples of the Core Objectives and patient-centered requirements. Providers must report on all 17 Core Objectives. Note item 15, which requires providers to provide a summary of care record for each transition of care or referral.

Report on all 17 Core Objectives:

1. Use computerized provider order entry (CPOE) for medication, laboratory and radiology orders
2. Generate and transmit permissible prescriptions electronically (eRx)
3. Record demographic information
4. Record and chart changes in vital signs
5. Record smoking status for patients 13 years old or older
6. Use clinical decision support to improve performance on high-priority health conditions
7. Provide patients the ability to view online, download and transmit their health information
8. Provide clinical summaries for patients for each office visit
9. Protect electronic health information created or maintained by the Certified EHR Technology
10. Incorporate clinical lab-test results into Certified EHR Technology
11. Generate lists of patients by specific conditions to use for quality improvement, reduction of disparities, research, or outreach
12. Use clinically relevant information to identify patients who should receive reminders for preventive/follow-up care
13. Use certified EHR technology to identify patient-specific education resources
14. Perform medication reconciliation
15. Provide summary of care record for each transition of care or referral
16. Submit electronic data to immunization registries
17. Use secure electronic messaging to communicate with patients on relevant health information

New Stage 2 Core Objectives:

- Use secure electronic messaging to communicate with patients on relevant health information
- Automatically track medications from order to administration using assistive technologies in conjunction with an electronic medication administration record (eMAR)¹²⁷

Recommendations:

Electronic records that are accessible, understandable, updated in a timely manner, and compliant with Stage 2 Meaningful Use requirements are not only recommended but are a mandate for providers.

Training and support for patients and caregivers is recommended to facilitate their ability to utilize the electronic records to their maximum benefit. Often the parents are more challenged than the youth.

Innovative technology solutions are also encouraged for this millennial generation of HIV-infected. This generation is so tech savvy the use of smart phone is often their first line of communication. They are the first generation of “digital natives”, and their affinity for technology could help facilitate improved compliance with care. Millennials are accustomed to instant access to information and will adapt well to new tech tools.¹²⁸

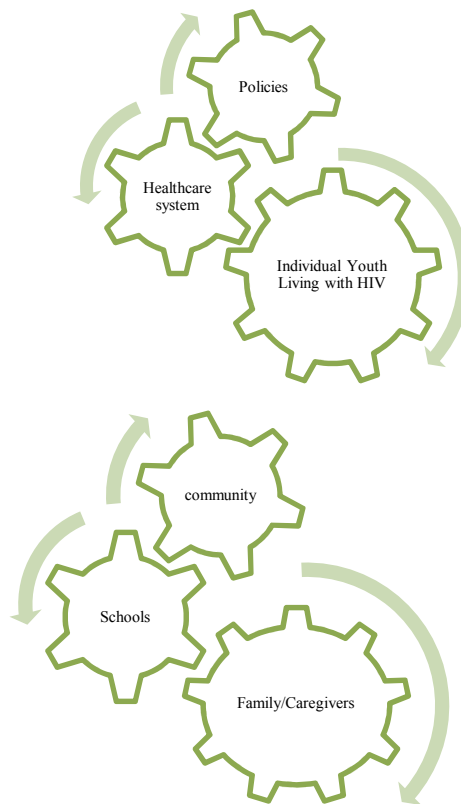
Also, the option of telemedicine is a natural fit for young people with HIV, with the common use of Skype, Face time and other live video feeds they would likely acclimate well to this option. They often travel a great distance for care and having the option to bridge visit schedules, access education, pharmacy needs, and other services would be well received by this age group.

D. Policy Implications and Plan for Change

To quote Karen Pittman, Co-founder and CEO for the Forum for Youth Investment, “Every community wants the best for its children and youth. They are the present and the future, the active ‘ingredients’ that combine to determine a community’s social, civic and economic health.”¹²⁹ At the heart of this research is that same vision for our young people living with HIV/AIDS. Their success along the complex journey toward responsible and healthy adulthood is paved by the complex systems and hurdles they must navigate. It is incumbent upon existing social and health systems to ease the journey as much as possible.

To visualize a bold theory of change, one must understand the interconnectedness of systems that improve or impede the well-being of young people living with HIV/AIDS. There must also be energy focused on building the capacity of existing systems and then establishing innovative connections between those systems. Often the greatest potentials to impact change exist between the systems. Like the synapses of nerve endings that do not actually touch but nonetheless connect and convey energy, systems that can enhance their capacity to connect can begin the critical journey toward collective impact. Fragmented systems abound in the social ecological world of transitioning youth with HIV. This research and plan for change strives to connect some of the fragmented systems for the youth and families traversing the journey toward healthy and productive adulthood.

Figure 4: Connecting Systems to Improve Individual and Population Health



The overall plan (Figure 4) for change is to stimulate improved systemic delivery of care and wrap-around services for the transition process from pediatric to adult HIV care. The process is informed by the correlation of findings derived from this qualitative, three-phase study of HIV-infected young adults and families with HIV-infected adolescents in the Triangle Region of North Carolina. This dissertation provides an assessment of their actual life experience during transition to adult HIV care services. Comparisons have been made to the recommendations from the AAP Committee on Pediatric AIDS for transitioning pediatric to adult HIV care and other evidence informed methods for pediatric to adult care transition. Through better integration of services across the system of care and enhanced awareness along the continuum of healthcare, the findings of this study augment the base of knowledge to manage this very challenging population of HIV-positive children and young adults. Specifically, I plan to share the patient-/family-informed HIV transition model and recommended policy and system findings across the local, state, and federal levels.

1. Local and Triangle Regions

Local and Triangle Region efforts will include working with the following: HIV health providers throughout the Triangle, hospital pediatric grand rounds presentations, and local HIV outreach bridge counselors to enhance current strategies for young people living with HIV/AIDS. The North Carolina Access Network of Care, an 11-county service delivery collaborative, includes five Ryan White Part C grantees. Two of these Ryan White Part D grantees will be excellent partners in advancing the recommendations. The regional ACA Marketplace Enrollment Teams could benefit from the findings regarding access and affordable medical insurance coverage perceived barriers for people with HIV. Additionally budget expansion requests and staffing allocations for local public health efforts can be addressed to facilitate implementation of the recommendations.

2. North Carolina State-Level Efforts

State level policy implications were highlighted in the recommendations. The obvious first group to collaborate with is the North Carolina Communicable Disease Branch, Department of Health. Many of the recommendations hold promise for funding and policy strategies. The PI will offer to work with the

state team to build a self-assessment tool for pediatric HIV practices across the state to promote awareness of the APP COPA recommendations and other key factors identified within this dissertation.

Policy implications and educational outreach are in order for the Medicaid Reform Workgroup. State Representative Nelson Dollar and Representative Marilyn Avila, both Wake County representatives, serve actively as chairs for various appropriation committees. The PI will work with state leadership to provide findings and recommendations for analysis and consideration of how to align the various federal, state, and private market HIV health plans (Ryan White funds, ADAP, Market place plans, Medicaid, social service programs, private or employee insurance plans, co-pays, and medication plans). Coordination of plans could align and maximize resources to achieve improved outcomes in a more cost-effective manner. A modified HIV insurance plan would coordinate options and customize plans for the individual and family needs. The findings of this study will also help state and federal funders to analyze the opportunities for Ryan White programs to seek PCMH designation and to become more engaged in the ACA Marketplace plans.

Opportunities exist for findings to be shared at multiple state conferences such as the NC Communicable Disease Conference, the HIV/STD Conference, the NC Mental Health Association, and the NC Public Health Association Conference. Also the HIV Round Table, which is composed of various state and national experts, will serve as a good platform to share recommendations. Various journals such as the *NC Medical Journal* will be an option for publication of findings and recommendations as well as the various professional societies such as the NC Pediatric Society, the NC Nursing Association, NC Public Health Association, and others.

3. National-Level Opportunities

Several potential venues exist to present abstracts at the national level: HRSA Ryan White conferences, the National Association of City and County Health Officers (NACCHO), the American Public Health Association (APHA), and the United States Conference on AIDS (USCA), as well as the National Network of STD Clinical Prevention Training Centers (NNPTC) which is a CDC-funded group of training centers created in partnership with health departments and universities. I will also seek

publication in journals such as the *American Journal of Preventive Medicine* (AJPM), the *American Journal of Public Health* (AJPH), and the *Journal of HIV/AIDS & Infectious Diseases* (JAID), which is an international online open access journal.

APPENDIX 1: NVIVO CODED KEY THEMES

Key Themes	# of Sources	Notation References
1. Mentor, Coach Support	10	71
2. Self-Efficacy	8	67
3. Stigma	9	61
4. Provider or healthcare	9	55
5. Written plan for transition	9	45
6. Mental Health	9	44
7. Medication Adherence	9	42
8. Access to Care	10	42
9. Education/ Career guidance	10	27
10. Positive deviance	9	26
11. Technology and EHR	9	24
12. Other extenuating issues	5	23
13. Viral Load and CD4	10	14
14. Legal issues and Sex	7	14
15. Race or Ethnicity	9	10
16. BHIV Characteristics	6	9
17. Perinatal HIV Characteristics	6	8

APPENDIX 2: CAUSAL LOOP CODING THEMES FOR CAUSAL LOOP DIAGRAM

Coding Key Themes for causal loop diagram

As of 12/30/14

Duke Clinic: Most report transitioning in early to mid-20's

ECU Clinic: Report 19- 21yo when transferred

Wake County: receiving from outlying areas of state when enroll in college

BHIV and PHIV experience varied significantly

Transition from Adolescent to Adult HIV Care Sources: 10 PHIV, BHIV, Caregiver Key Informant Interviews			
<i>Key Themes</i>	<i>Causal themes: 4 categories, Cross Connections, Archetypes, Trajectories, and Solutions</i>	<i>Factors that improve transition or control of HIV</i>	<i>Factors that worsen transition or control of HIV</i>
1. Education/ School/ College/ University	<ul style="list-style-type: none"> • Mentor or facilitator of process links • Awareness of scholarships and support • PHIV/BHIV variance in level of support • All PHIV have some advanced education • BHIV have limited support for educational support 	-Someone to guide the process for education. - SW engaged actively - Supportive healthcare team - Supportive family -Awareness of scholarships and financial assistance -Ability to have a good plan for meds in college(confidentiality, access, supportive directions on how to manage) AAP COPA recommendations stress need	-Drop-out of school -Loss of extra-curricular activities in high school (due to fear of HIV disclosure) - some healthcare providers do discuss need for education however, others do not and do not include the caregivers in discussion
2. Job/ occupation/ career	<ul style="list-style-type: none"> • Related to mentor or facilitator of process • Challenges specific to HIV • Adequacy and availability of jobs • Issues with employer medical insurance • BHIV receive 	-Someone to guide meaningful and clear direction for career or employment - Respect for employee confidentiality -insurance plans and assurance of confidentiality	-Lack of education lessens employment options -Employers asking too many questions about need for health care visits - Concerns re.

	limited support for job searches		<p>medications and health plans</p> <p>-Concerns about having to discuss with employers and Human Resources what types of health plans(WC1)</p> <p>-Stigma of having to ask off for medical appointments on a regular basis (WC1)</p>
3. Technology/ electronic records/ online files/ app tools	<ul style="list-style-type: none"> • Support and training to use technology contribute to user access • Availability of technology resources • Pediatric versus Adult healthcare • Telemedicine 	<p>-Potential reliability of access</p> <p>-Some would like to see trend analysis of lab values to better understand the progress of care. (WC 10)</p> <p>-Apps as reminders of appointments and meds was viewed positively interviewees.</p> <p>-telemedicine could benefit those that travel great distance or for intermediate visits for ancillary services.</p>	<p>-Lack of awareness of electronic records is a commonality. Providers could benefit patients by making them more aware of records and how to utilize.</p> <p>-Lack of access to internet</p> <p>- None of the patients or caregivers had been coached on their rights to comprehensive access of their health records</p> <p>- limited portions of records available to patients</p> <p>- concerns of confidentiality</p> <p>- Some of the caregivers had never had instructions on how to access EHR'S, also no computer</p>

			availability - Providers are still not using text or apps as a reminder - Not all providers can access records across systems (MH/SW/ Clinical staff, etc.)
4. Access to care -Provider/ primary/ care -Provider secondary providers/ Emergency department/ urgent care	<ul style="list-style-type: none"> • Ease of access is variable for various locations • Time required for visits • Ease of use • Issues of confidentiality • Many use ED and Urgent care for healthcare • Most do not use the HIV Healthcare providers for general health needs • AAP COPA Recommendations • Lit review Weiner et.al. • Adequate accessibility to testing sites for earlier diagnosis for BHIV's • Parents can be a strong influence on BHIV's being tested and accessing care • Health care payer systems may dictate level of access to care 	-Adult visits take less time (average 30 minutes as compared to 2-3 hours for peds). - need a good plan for transition of health care coverage when young adults turn 26 years old and age out of coverage. (parents health coverage, Medicaid, or the Foster Care Medicaid system) - Health providers and staff are welcoming and convey genuine interest in patients - Some prefer the briefer and more focused adult clinic visits while others like the extended conversations - adequate health insurance -A more PCMH type structure of care.	-Can take an entire day to have medical visit due to travel (lack of trust in local providers) -lack of a written plan (Weiner et.al) - Adult health system has fewer supports (SW's, others) but many patients voiced that there are still needs - Unfriendly clinical staff that leave the impression this is a job. Not as people oriented. - Co-pay that is too high for meds and care may hinder access and adherence -some BHIV's expressed difficulty in access testing for initial diagnosis - Need for even

			<p>the front desk and lab techs to be a bit friendly (WC 01)</p> <p>- WC 02 reports Ped clinic had the feel of a relationship. Not so much with Adult clinic</p> <p>- some clinics only serve HIV needs, no other primary care needs.</p>
5. Access/Time/ travel/ distance	<ul style="list-style-type: none"> Many prefer travel to fear of disclosure of status in community (stigma) Many travel > 1 hour Cost associated with travel and time away from work 	<p>-perceived efficiency of adult clinics compared to time in ped visits (30min vs 3 hours)</p> <p>-Use of local ED's and Urgent care for general non-HIV needs</p> <p>-Gas cards were given to some of the Caregivers to help with cost of transportation</p>	<p>-perceived efficiency of adult clinics compared to time in ped visits (30min vs 3 hours)</p> <p>-Transportation barriers to distant HIV care (WC 09)</p> <p>-fear of employers questioning frequency of medical care appointments</p>
6. Cost/ expense/ affordability/ insurance	<ul style="list-style-type: none"> Insurance factors Challenges with Medicaid enrollment may be associated with away from home mail address or other reasons ADAP is extremely helpful to address cost of meds when other options not available but lose benefit when insured. 	<p>- Adequate insurance coverage</p> <p>- Transition from parental needs that is planned</p> <p>-Education on the various options and guidance in selection</p> <p>- coordination between payer systems (state/fed/private) would help</p> <p>- hope for new ICAP system in ADAP</p> <p>- There is a need for</p>	<p>-Travel adds to cost</p> <p>- Co-pays can be excessive</p> <p>-Uncertainty in new insurance products , need assistance in processes</p> <p>- missed re-enrollment in Medicaid</p> <p>- when in college may miss communications</p>

	<ul style="list-style-type: none"> • Awareness of new market place insurance products coverage and level of coverage needed • Confusion related to co-pays, ADAP, and new options that may interfere with receiving meds and care. • There is a need for bridge counselors to assist with the complicated processes for insurance decisions and sign ups 	bridge counselors to assist with the complicated processes for insurance decisions and sign ups	<p>-mail</p> <p>-difficulty with the online process and information on most appropriate product to meet their needs.</p> <p>Lack of clear guidance for HIV population</p> <p>- Deductibles on private insurance cause “WC 03. And the thing about it is I have Blue Cross Blue Shield because I do work for the state I was teaching when I went out on disability and I have Blue Cross Blue Shield, but the visits are so costly. I mean one time between the blood work and the visits it was \$50 for both of them, and every 3 months so you double it, no. triple it because I was going too. And all I say is don’t look at my credit report during that time, I’ll put it that way ha ha ha....”</p> <p>- disconnect between systems</p>
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<p>7. Stigma/ confidentiality/ trust/ breech/gossip</p>	<ul style="list-style-type: none"> • Many experience breeches in confidentiality (family/ friends/ medical/ other) • Major issue with fear of disclosure • Breeched confidentiality at local providers (WC 01,02,09, 04) 	<p>-Adherence to confidentiality in family and medical care</p> <p>-Sensitivity in social settings</p> <p>-More education for the general public on the real facts related to HIV</p> <p>- relationships that value trust</p> <p>- legal protection</p> <p>- cultural sensitivity and confidentiality education for health providers (especially those that encounter HIV less frequently)</p>	<p>-Fear of breech in confidentiality</p> <p>-lack of sensitivity in school and social settings – negative talk and generalities</p> <p>-many travel great distances to avoid using local healthcare due to lack of trust</p> <p>- Poor counsel from (Wilson) local health providers related to disclosure of HIV status to sports teams</p> <p>-Caregivers have issue of stigma too and have felt stigmatized</p> <p>- Lack of cultural sensitivity in some of the local clinics and health departments</p> <p>- work place issues that jeopardized confidentiality</p>
<p>8. Relationships/ dating/ friend/ and supportive family/ caregivers</p>	<ul style="list-style-type: none"> • More successful outcomes generally if there are stable relationships • Challenging to build new relationships due to trust issues • Generally relationships can be complicated, trust is 	<p>-Supportive caregivers and healthcare teams helpful</p> <p>- Conferences/retreats that specifically address the various issues of HIV in adolescence.</p> <p>Prolonged time with HIV-infected peers is helpful.</p>	<p>-breech in confidentiality</p> <p>- Trust issues</p> <p>- Caregiver/ guardians describe a positive relationship with young adults due to the need for supportive care</p>

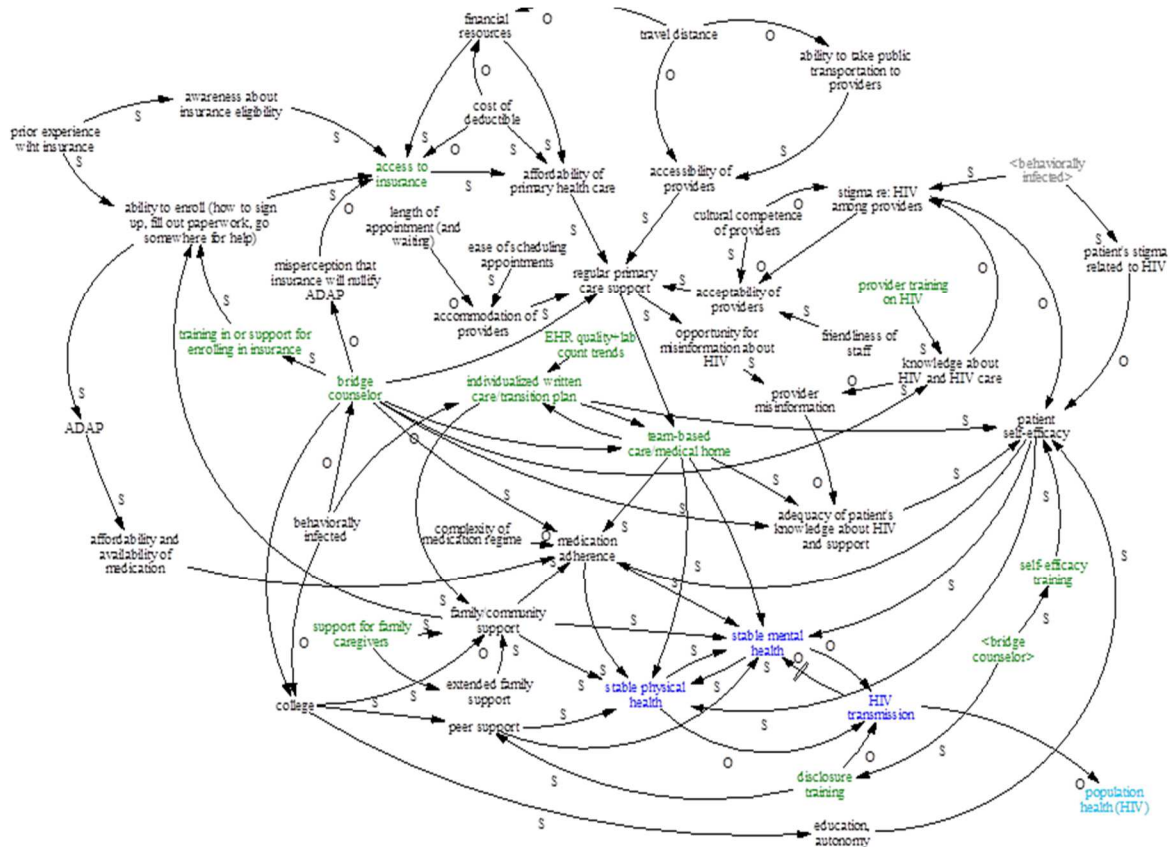
	a major issue	<ul style="list-style-type: none"> -Coaching scenarios on how to disclose to others -Role Play practice with peers and SW's - Some describe a strong spiritual relationship - WC 01 and 02 noted that peer support from other HIV-infected young people may be helpful 	<ul style="list-style-type: none"> - All PHIV's have one or both parents deceased, incarcerated. - most indicated lack of strong father figure -many have experienced death of one or both parents which leaves a void
9. Mental health/depression	<ul style="list-style-type: none"> • Noted thoughts of suicide and depression in multiple interviews • Concern of hurting self • Chronic nature of disease is noted as overwhelming at times. • Literature reveals pervasive nature of MH • AAP COPA holistic care recommendations 	<ul style="list-style-type: none"> -Careful monitoring of MH status and appropriate MH care -more frequent visits to monitor if on meds for depression - Pediatric Clinics more probing and assess MH status more frequently (WC 01) -Emotional and logistical support during the transition is beneficial - importance of long-term relationships with health team and SW's like Mary(WC 01) - Parental involvement a some level to support the process- while allowing for independence of the young adult - It may also be helpful to have a peer mentor or support as transition -PHIV HAVE more support 	<ul style="list-style-type: none"> -frequency of visits can be a challenge for work and school - Unless the patient volunteers that there are issues the Adult HIV healthcare team may not ask about MH -Adult clinics lack method to address the harsh reality of a chronic life-long disease. - Adult clinics can be a rude awakening after a warm and welcoming Ped clinic. - Frequent changes in health care team and SW's can be detrimental - Crucial role of support during transition – a bridge person(SW) that is consistent between to two

			<p>health care settings</p> <ul style="list-style-type: none"> -The chronic nature of and burden of a lifelong disease is often not addressed by health care providers - Caregivers expressed a significant strain on their physical and mental status in caring for the HIV-infected youth - BHIV interviews noted limited or no help with this area of care.
<p>10. Adherence/faithfulness/awareness of Viral load/ VRL/ CD4</p>	<ul style="list-style-type: none"> • Prompters (technology and family or friends) • Some voiced it would be great if there could be a time released med or injectable. • Adherence to meds is a major issue during transition • Side effects influence • Unstable housing and living conditions influence 	<ul style="list-style-type: none"> -Strong mentor or coach -Ease of medication use and schedules -Medication preference is variable and some prefer the 1x day others not - Consistent pharmacy helps - ADAP helps with \$ -App to remind when to pick up meds is a positive -Self Efficacy- (Realization that the responsibility actually is the individuals- maturity- WC 1) -Adult clinic more inclined toward electronic health records than Peds 	<ul style="list-style-type: none"> - Not sure how to pay for meds compromises -other unstable SE factors - May forget to pick up meds -As transition to adult others are not reminding you your meds and appointments (poor Self-Efficacy -Adult clinics do not have the same extra support systems as ped clinics- Maybe helpful to have a mechanism of reminders and support. -fear of losing ADAP if

			insured
11. PHIV/ born with it/	<ul style="list-style-type: none"> • Variance in educational levels • Level of support for physical and emotional needs • Appear to have significant variance in issues that confront PHIV and BHIV patients 	-Parental involvement in process of transition -Receive more SW support than the BHIV's - in general more support systems for needs	- loss of parents - Unstable MH, depression - BHIV'S lack supports
12. Transition Plans and Written plan that is shared with patient/or family for transition	<ul style="list-style-type: none"> • None of the KII's reported having a copy of written plan which is recommended by the American Academy of Pediatrics • BHIV patients do not receive the same level of planning for adolescent to adult care. Significant gaps • BHIV's still need support of parent type figure if available. 	-Most stated that they believe a written plan may be helpful. -A gradual process of education and transition is preferred (confirmed in interviews and AAP Recommendation s) -Treating the late adolescent more like an adult. -- automated transfer of records, many positives limit confusion on the appointment schedules -more involvement of parent or caregiver when there is a supportive caregiver is helpful -age appropriate topics and methods - Parent can be intellectual and emotional support during transition	-No clear guidance on the process of transition can leave patients unprepared. -Helpful for medical team to begin treating patient more like an adult in later stage of adolescence. -Unclear methods on how records will transfer can precipitate confusion - BHIV's often start with adult care so lack many of the supports that build self-efficacy " Hell, I can't even get my doctor to give me a call back. I have been trying for weeks. I see her 1 time every 3 months and she is never in. Sometimes I need help."

13. Legality and disclosure status	<ul style="list-style-type: none"> • Needs to be reinforced periodically • Age appropriate • All were aware and understood why it is there 	-Individualized education: Some need more discussion than others? - age appropriate reinforcing of education - support for adherence	-can be fearful - threatening attitude
14. Other extenuating issues	<ul style="list-style-type: none"> • Other chronic diseases such as diabetes or asthma, ADD, • Dental services • Other wrap around services 	- PCMH that serves more than just HIV - Holistic care - Links to ancillary services	-HIV health care provider may not always address the other health issues -May not ask about other issues -May not know other resources
15. Self-efficacy	<ul style="list-style-type: none"> • Access to health records • Training education on how to disclose • Training on care management • Access to health insurance is needed • Parents can be a bridge to self-efficacy 	-Coach/ Mentor can positively influence progression to self-efficacy - classes or role-playing for disclosure and self-efficacy - adequate career and educational level aids - SW helps	-BHIV patients not always given training needed -Compromising confidentiality -Lack of resources, job, and insurance.

APPENDIX 3: SYSTEM DYNAMICS MODEL- CAUSAL LOOP DIAGRAM



Variables and Arrows

Start with “variables”, noun/noun phrases that can go up or down, and arrows that connect them. Arrows indicate that a change in the first variable leads to a change in the second variable, all else equal.

Note: We label the arrows here with “O’s” and “S’s” because two variables are moving in opposite directions and two are moving in the same direction, respectively. Example: When health (physical or mental) goes up, it triggers a decrease in HIV transmission (& vice versa).

O’s = variables move in opposite direction S’s = variables move in the same direction

The diagram starts with the end in mind and incorporates the variables that support or oppose the desired outcome of a healthy individual and decreased incidence of transmission of HIV. Successful transition in care and decreased transmission of HIV are dependent upon stable mental and physical health. Stable mental health supports stable physical health and vice versa. Stable mental health and physical health decrease HIV transmission. All other factors are the variables that support or oppose this outcome.

APPENDIX 4: ACUITY RANKING FOR HIV CASE MANAGEMENT STAFFING ALLOCATION

Wake County Public Health Division HIV Outreach Team Acuity Ranking Scale for HIV Case Management Staffing Allocation

Acuity level	1	2	3	4	5
Ranking indicator descriptives	<ul style="list-style-type: none"> • Virologically stable (cd4 >200, VL <20 for more than a year) • Stable housing/basic needs • Adheres to appointment schedule 	<ul style="list-style-type: none"> • Virologically stable • Misses some appointments but does reschedule • Stable housing • Needs occasional transportation • Re-start HAART (not treatment naïve) 	<ul style="list-style-type: none"> • >1 STD in a 6 month period • Transfer from pediatric practice • Misses appointments w/o assistance • Needs external assistance (no support system) • NOT virologically stable • Unstable housing (not homeless) • New HAART start (weekly calls) • Almost MIA 	<ul style="list-style-type: none"> • Acute domestic violence • Homeless • Peri-incarcerated • Pregnant & not in care • Cd4 <200, VL>400 • DOT people • Unstable mental health • Newly diagnosed (cd4<200, vl>400) • Re-engaged in care people 	<ul style="list-style-type: none"> • People living with HIV in hospital with opportunistic infections • Worsening co-morbidities <p><u>*Client should not be on stage 5 for extended timeframe. Emergency cases only*</u></p>
Frequency of bridge counselor contact	Face to face every 6 months and phone calls as needed	Face to face every 6 months, phone calls every 3 months, & as needed	Face to face every 3 months, 2x/monthly phone calls, & as needed	Daily phone calls, weekly face to face, & as needed	Daily phone calls, 2x/weekly face to face, & as needed

**Frequency contact on the bottom rows and levels on the top

Overview of acuity ranking indicators: This acuity staffing tool was designed by Wake County Public Health staff based upon similar hospital models utilized by the PH Division Director in previous hospital-based worksites. Though acuity staffing is seldom used in public health settings, “acuity can be defined as the measurement of the intensity of...care required by a patient,”¹⁰³ or client. An acuity-based staffing model adjusts the staff: client/patient ratio according to the client/patient’s needs. Client needs may range from minimal assistance to needing a dedicated caseworker on a daily basis.¹⁰⁴ This ranking instrument serves to assess and prioritize needed client services.

The instrument helps with addressing identified barriers to improving health outcomes and protecting population health by recognizing factors such as social determinants, physical and mental health status, and compliance with care regimes. Because the scale provides a tool to target individuals who have acute needs requiring considerable staffing attention, the Wake County Public Health Division is utilizing the scale to more efficiently allocate staffing resources. The acuity scale was designed specifically for HIV positive individuals in order to address the particular health and social determinants.

Due to the fact that public health officials constantly seek mechanisms to maximize utilization of scarce resources and simultaneously assure services to the most at risk clients, this acuity ranking tool supports a predictable staffing formula for patient assignments in need of case management. The tool was developed in conjunction with HIV bridge counselors, outreach staff, and clinical staff. The acuity formula is currently being utilized to assure appropriate staffing level and maximize benefit to clients most need of services. See the list of 21 ranking indicators below.

1. Medical Home stability and adherence to appointments
2. HIV disease progression - Virologically stable, CD4>200 and viral load undetectable, no history of opportunistic infections or hospitalizations.
3. Disease co-morbidities
4. HIV knowledge- Client is able to articulate a clear knowledge of HIV (transmission, prevention and progression.
5. Health literacy- Client has the capacity to obtain, process, and understand health/prescription information with no assistance.
6. Adequate knowledge of HIV medications.
7. Treatment support- Client has complete support from all family, friends and peers.
8. Medication Adherence
9. ARV side effects- managed or no reported side effects
10. Health insurance- adequate coverage.
11. Mental Health- client reports no history of mental illness
12. Addiction- no history of substance abuse
13. Risk reduction- Client abstains from risky behavior of any type by practicing safer practices or has no recent report of STDs.
14. Activities of daily living- Client is independent in all domains
15. Nutritional status- Client reports no issues
16. Oral health- Client has access to dental care and reports no oral hygiene issues
17. Financial stability- Client able to meet obligations for basic needs
18. Living situation- stable housing
19. Legal issues- no past or present legal issues

20. Dependents- Client needs no assistance with dependents

21. Children- Client has no children living with him/her

A more comprehensive scoring assessment tool may be obtained from Wake County Human Services Public Health HIV Outreach Team at 10 Sunnybrook Rd, Raleigh NC 27620. Below is a summation of the 21 key indicators used to evaluate client's acuity level and staffing support needs.

Scoring Matrix for Acuity Case Management

Total Points Scale				
24 – 35	Medically stable without Medical Case Management (MCM) assistance	Able to manage supportive needs without assistance	Self-management	Face to Face at least once every 6 months for reassessment – phone contact as needed
35 – 50	Medically stable with minimal MCM assistance	Able to manage supportive needs with minimal MCM assistance EXCEPT when in crisis	Short Term management	Face to face as needed to divert crisis and every 6 months for reassessment – phone contact as needed
50 -80	At risk of becoming medically unstable without MCM assistance	Able to manage some supportive needs without assistance but needs MCM assistance for other needs	Basic Management	Face to face at least once every other month or as needed – phone contact as needed
80 – 100 OR HOPWA voucher	One appointment away from becoming medically unstable without MCM assistance	Support systems are not adequate to meet client's immediate needs without MCM assistance	Moderate Management	Face to face at least every month – phone contact as needed
100 – 120 OR Newly Diagnosed	Medically unstable and in need of comprehensive MCM assistance OR cognitively or physically challenged	Has no support system in place and unable to manage supportive needs without MCM assistance	Intensive Management	Face to face at least every other week – phone contact as needed

Transitional Care Stakeholder Action Planning Session



Transitioning from Adolescent to
Adult HIV Care
February 21, 2015

Agenda for today

10am- 1pm

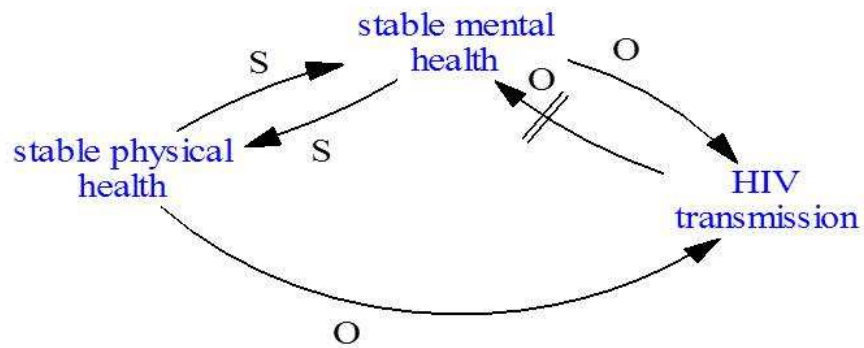
Task	Responsible	Time allotted
Welcome, introduction of today's agenda, and confidentiality statement	Lechelle	10 minutes
Overview of research project, background and purpose of Transition Process review	Sue Lynn	10 minutes
Question and answer if needed	Lechelle/Kristen/ Sue Lynn	10 minutes
Snacks and Ice breaker	Lechelle	30 minutes
Review of Key Informant Interview findings and Top 10 ranking exercise	Lechelle/SueLynn	30 minutes
Divide into sub-groups to review key finding categories	2 groups	30 minutes
Break		10 minutes
Re-unify group for final feedback – Connection Circle	Lechelle and Kristen	30 minutes
Closing comments, question/answers, and next steps	Lechelle/ Sue Lynn	15 minutes

Research background information

A Patient/Family Centered System Dynamics Approach- Transitional Care for Pediatric to Adult HIV Patients

- *Why is this research important?*
- *How was the information gathered?*
 - *Interviews with HIV + young adults or family members*
 - *Literature reviews*
- *Focus group feedback as part of the final phase*
- *Crucial role of focus group to the final recommendations*

Core concept from interviews: Cannot separate physical and mental health



S's = variables move in the same direction

O's = variables move in opposite direction

Ice Breaker

- Player Exercise used to explain systems causal loop

10 Keys Factors that shape successful transition

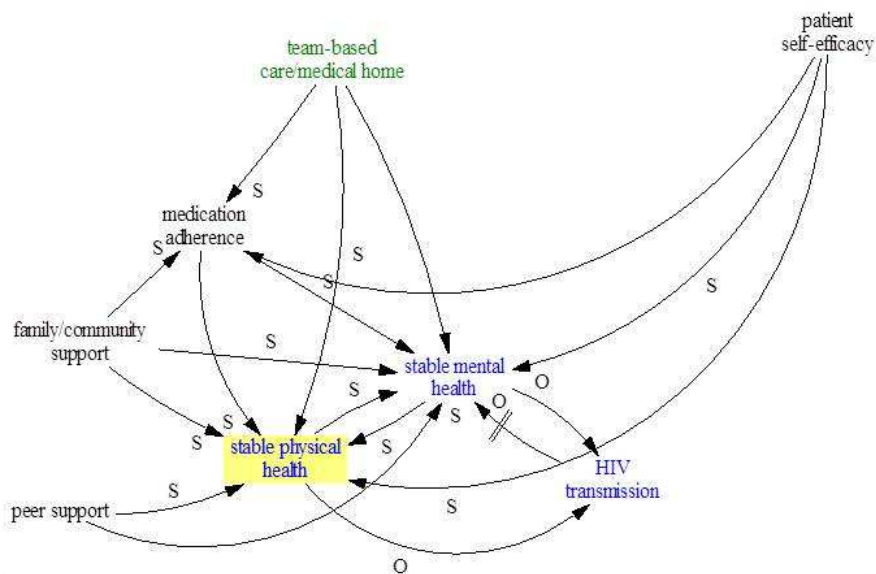
- Family/caregiver support
- Adequate medical insurance coverage
- A Patient-centered medical home with access to “wrap-around” services
- Technology support and Electronic Health Records access
- Individualized physical /mental health care plan
- Strong self-advocacy
- Age-appropriate educational support
- Address stigma issues
- Career guidance and planning
- Ongoing provider support for entire transition process (Medical and Bridge Counselor)

[illegible]

What can strengthen physical health outcomes?

- Patient-centered medical home with access to “wrap-around” services
- Strong self-efficacy, self-worth and ability to effectively speak up for self
- Family/ caregiver support
- Adequate medical insurance coverage
- Individualized physical /mental health care plan
- Medication adherence supports
- Age-appropriate educational support
- Ongoing provider support for entire transition process (Medical and Bridge Counselor)

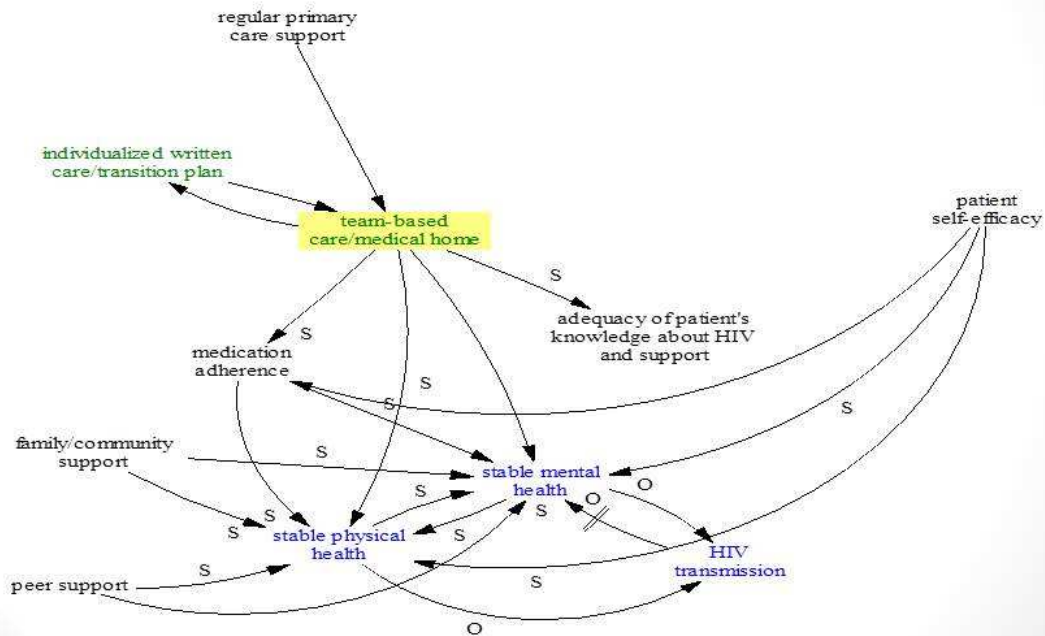
Continuing the illustration...



What can strengthen mental health outcomes?

- Strong support systems (family, friends, and health teams)
- Individualized physical /mental health care plan
- Adequate health insurance coverage
- Ongoing bridge counselor support throughout transition
- Strong sense of independence
- Must address issues of stigma
- Adequate knowledge base
- Career guidance and planning

Continuing further.....



Team A and Team B please analyze and provide feedback
Decide spokesperson for group
Report out when we return to big group
Final thoughts or revisions?

FEEDBACK ON FOLLOWING SLIDES

(12)

What really impacts the ability of Family/Guardian/Others to provide Support?

Make it easier

- Community support for family
- Good relationship with providers
- Individualized written care plans
- Bridge Counselor
- Educational support
- Support for caregiver

Make it harder

- Unstable financial circumstances
- Lack of support from providers
- Unstable mental health

What is most important in assuring adequate medical insurance?

Make it easier

- Ability to access an insurance plan
- Financial affordability
- Prior experience using insurance
- Awareness of insurance eligibility requirements
- Bridge counselor or other external support to assist

Make it harder

- Misperceptions regarding loss of other benefits (ADAP)
- Provider does not accept plan (Preferred provider)
- Cost of deductibles
- Cost of insurance

What should the patient-centered medical home assure and avoid?

Make it easier

- Individualized written care plans
- Inclusive of primary care
- Inclusive of “wrap-around” services (education/SW/ referral links for specialty services)
- Ease of scheduling
- Professional and friendly staff
- Availability after hours

Make it harder

- Travel distance
- Appointment scheduling and timing
- Lack of connection with primary care providers
- Lack of cultural sensitivity
- Transition too soon

What issues must be addressed to assure the physical /mental health care plan is individualized?

Make it easier

- Ease of access to confidential electronic medical records
- Patient involved in development of plan
- Family involved, when it is appropriate
- Entire health team contributes to plan

Make it harder

- Not updated regularly
- Inaccessible to patient and family

How can bridge counselor or SW support patient self-worth and independence?

Make it better

- Available to patient throughout transition
- Active role in health-care team
- Provides written plan for key hurdles that is shared with patient
- Adequate understanding of legal issues
- Actively addresses issues of stigma

Make it worse

- No bridge counselor available to support
- Health Team not current with new market place insurance plans
- Difficult to access BC or SW
- Does not connect with family or other supports

How to assure age-appropriate educational support?

Makes it easier

- Incorporated into health plan
- Encourages independence/self-confidence at every age level
- Addresses issues of stigma
- Inclusive of behavioral health needs
- Behaviorally infected and perinatally infected needs may differ
- Camps or forums with education experts

Makes it harder

- Lack of a trusted source outside family
- Primary care provider that lacks current standards of care

What encourages medication adherence?

Makes it easier

- Team based medical home support
- Family/caregiver support
- Reminder tools/apps
- Adequate patient independence or self-confidence
- Adequate education on meds
- ADAP and /or Affordability of meds
- Home-delivered meds

Makes it harder

- Complexity of med regime
- Cost of medications / deductibles
- Behaviorally unstable person
- Unstable housing
- Lacks basic needs

How can Electronic Health Records help?

Makes it easier

- Complete access on records for self-care
- Patient understands how to use records
- Self- monitoring improves compliance
- Trends in lab values
- Medication listing
- Portable records for ease of transfer to new provider
- Long-term health record

Makes it harder

- Lack of access by providers
- Lack of internet access in patients home
- Concerns of confidentiality
- Inability to interpret Electronic records (added by participants)

How to deal with stigma issues?

Makes it easier

- Adequate understanding and educational background on HIV
- Supportive family
- Supportive peers
- Behavioral health support
- Respect for confidentiality issues
- Community support

Makes it harder

- Lack of self-confidence or self-efficacy- ability to stand up for self
- Lack of cultural competency among providers
- Misinformation among caregivers and providers

How can we aid career guidance and planning?

Makes it easier

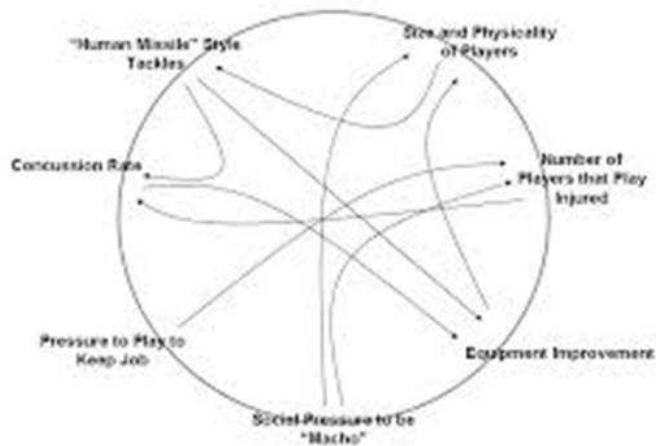
- Bridge counselor
- Family support
- Scholarship support
- School counselor support
- University and Tech school tours
- Retreats/forums for career planning

Makes it harder

- Drop out from school
- Lack of supportive processes and awareness
- Financial barriers
- Employer health history questions

Connection Circle Exercise

What contributes to concussions? (<http://bradsiragusa-ia341.blogspot.com/2010/02/nfl-concussions.html>)



Team A
Team B
Connection Circle with Kristen
Consensus on key points
Next steps
Final statements

BIG GROUP REPORT OUT

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