

RYAN WHITE PART D APPLICATION  
Part D  
Part D Youth Initiative  
State General  
FY 2010

FEBRUARY 20, 2009

JOHNS HOPKINS UNIVERSITY  
PEDIATRIC & ADOLESCENT HIV/AIDS PROGRAM  
INTENSIVE PRIMARY CARE (IPC)

The Johns Hopkins Hospital Children's Center  
Rubenstein Child Health Building  
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Non-profit educational institution and academic health center

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Part D  
Part D Youth Initiative  
State General

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**1. ABSTRACT/ PROGRAM SUMMARY**

Service categories: Outpatient Ambulatory Health Services; Mental Health; Medical Case Management/Treatment Adherence; Non-Medical Case Management; Outreach; Psychosocial Support

Program design: Intensive interdisciplinary comprehensive care program integrating health and support services in a single clinic for infants, children, youth, women, and families living with HIV/AIDS.

Targeted populations: Infants (0-2) Children (2-12) Youth (13-24) Families

Program interventions and services: HIV diagnosis, evaluation, treatment, monitoring; intensive adherence support; transitions program youth to adult; on site mental health evaluation & treatment; intensive case management; outreach; risk reduction counseling; life skills training & support; mindfulness-based stress reduction

Geographic region: State of Maryland, especially Central Maryland

Service delivery sites: IPC Clinic, located in the Harriet Lane Clinic adjacent to Johns Hopkins Hospital in East Baltimore; Home visits

Primary objectives: Clients will adhere to recommended HIV treatment as evidenced by drop in viral load and maintenance of CD4 count. Clients will become independent in medication adherence. Clients will transition successfully to adult HIV clinics. Clients will transition to independent living as young adults. Clients will cope successfully with the stresses of living with HIV and its complications.

Number of clients to be served: 200 HIV-infected children & youth; 25 HIV-exposed newborns; 75 affected family members

Anticipated outcomes: Short term outcomes such as non-detectable viral load and normal CD4 count and longer term outcomes such as survival into adulthood and transition to adult clinics result from the integration of all categories of service by the interdisciplinary team.

<u>Service</u>	<u>Request</u>	<u>Clients</u>	<u>Cost per client</u>
Outpatient Ambulatory Health	\$80,246	225	\$357
Mental Health	\$96,602	150	\$644
Medical Case Management/ Treatment Adherence	\$168,155	200	\$841
Non-Medical Case Management	\$41,746	80	\$522
Outreach	\$49,589	500	\$99
Psychosocial Support	\$183,352	300	\$611

Funding Stream

Part D	\$265,614
Part D Youth	\$230,352
State General	\$123,725

## 2. NEED STATEMENT/TARGET POPULATION

a) The state of Maryland ranks 18th out of the 50 states in population size (US Census Bureau 2008), yet it ranks 9th in cumulative AIDS cases and *1st in AIDS incidence rate* (29.0/100,000) (CDC 2008). Within the state of Maryland, the epidemic has its stronghold in Baltimore City. Through December 2007 nearly half of the 32,811 documented cases of people living with HIV/AIDS (PLWHA) in Maryland reside in Baltimore City (Maryland DHMH 2008). In 2006, 48% of newly diagnosed cases of HIV infection in the state of Maryland occurred in Baltimore City (Maryland DHMH 2008). Baltimore has the *2nd highest incident AIDS case report rate* of any major metropolitan area (37.7/100,000) (CDC 2008). These disease rates have qualified Baltimore as an Eligible Metropolitan Area (EMA) for nineteen consecutive years. According to the international rates published by UNAIDS, Baltimore's adult prevalence rate for PLWHA is comparable to those in the Caribbean and higher than all other regions of the world except sub-Saharan Africa (UNAIDS 2004).

Of particular concern is the epidemic's growing impact on Baltimore City's adolescent and young adult population. Forty-five percent of Maryland's 2,656 reported HIV-positive adolescents and young adults aged 13-29 reside in Baltimore City. As of December 31, 2006, there were 262 children and adolescents aged 0-19 and 1056 young adults aged 20-29 with a reported HIV/AIDS diagnosis living in the city of Baltimore. In the State of Maryland as of the same date, there were 470 children and adolescents aged 0-19 and 2389 young adults aged 20-29 with a reported HIV/AIDS diagnosis (Maryland DHMH 2008).

The pediatric/adolescent communities most affected by HIV/AIDS are predominantly African-American, equally male and female, predominantly adolescent, of diverse sexual orientation, and predominantly low income or unemployed. The demographic breakdown of the clients we serve is consistent with that of the HIV/AIDS infected population in Baltimore City, where 88.5% of HIV-infected persons are African-American (Maryland DHMH 2008). Though women represent only 37.7% of reported HIV/AIDS cases in Baltimore across all age groups, in the pediatric and adolescent age group 46% of HIV/AIDS infected persons were female as of December 2006 (Maryland DHMH 2008). Increasing numbers of youth are uninsured. Increasing numbers of youth have substance use and mental health disorders. Most clients come from families with substance use problems.

The number of adolescent survivors of perinatal HIV infection is growing, with increasing problems in school, with the law, with family disruption, orphan status, and serial foster homes at a time when their HIV disease is progressing. As this clinic population gets older, many clients lose their health insurance and are no longer eligible for Medical Assistance.

b) Our Program assesses needs through monitoring epidemiologic trends, assessing barriers to care through community outreach, and in depth assessment of the needs of clients who access care. This proposal is in response to this ongoing needs

assessment. Although there are common issues across all the populations we serve, the target populations for this service proposal cluster into the following groups:

- Youth (13-24) who were born with HIV and have survived into adolescence and young adulthood
- Young men (13-24) who acquired HIV through sex with other men
- Young women of childbearing age (13-24) who acquired HIV through sex with older men
- Children (2-12) born with HIV
- Infants born to HIV-positive mothers
- Families (self-defined) and caregivers of all of the above groups

Unmet Need refers to HIV infected persons who are not “in care.” Our program has successfully linked with outreach programs providing community based counseling, testing, and referral services for young MSM in Baltimore. We are linked with prenatal care programs that offer CTR services for pregnant young women. These linkages provide access to care for HIV positive individuals and our program works successfully to maintain these clients in care. With the increasing incidence of syphilis and gonorrhea among heterosexuals and MSM in our community, we can assume that many youth are also becoming infected with HIV. Client specific barriers to care include depression, isolation, and addictive behaviors while system barriers include lack of health insurance and lack of sufficient income to maintain a safe and healthy lifestyle.

Service Need refers to gaps in service access or delivery for HIV positive clients.

Our program strives to fill the gaps in care for the population of HIV-exposed and infected infants, children, youth, women, and families in the State of Maryland. This unique population requires a comprehensive approach that is competent in providing care that is developmentally appropriate and sensitive to issues of age, gender, sexual orientation, and race/ethnicity. The Johns Hopkins Pediatric & Adolescent HIV/AIDS Program based in the IPC clinic is one of the premier programs nationally servicing this population. Continuation and expansion of this program is critical to filling the gaps in the State of Maryland.

Both perinatally and behaviorally infected adolescents require *intensive psychosocial support services integrated with HIV medical care*. Advances in HAART have enabled perinatally infected children to live much longer than originally expected, and are now adolescents and young adults who have unmet developmental needs stemming from the expectation that they would not survive into adulthood. For many of these patients, medical needs have superseded social, educational, and developmental goals for much of childhood and adolescence. In addition, many perinatally infected children are orphaned at an early age and may lack consistent adult role models. As they reach late adolescence and young adulthood, they are expected by family members and society to take on adult responsibilities relating to housing, social services, financial management, and employment, but lack the skills necessary to succeed. There are early warning signs in adolescence in their failure to adhere to treatment regimens and attend school,

oppositional behavior, substance abuse, and risky sexual behavior. We believe that early training in goal setting and self advocacy will enable them to successfully take on the responsibilities of self care.

For behaviorally acquired adolescents, the HIV diagnosis is a profound interruption in their development. On our experience with these patients, their acquisition of HIV is often a symptom of a lack of adult guidance during their transition through adolescence. These patients exhibit some of the warning signs described in perinatally infected patients, including failure to attend school, substance abuse, and risky sexual behavior. At the time of diagnosis, they are asked to take on the sudden and significant responsibilities of managing their illness and their lives under the pressure of dire health consequences. Without guidance and support, they slip into denial and become non-adherent and noncompliant. This outcome not only endangers their own health, but increases the risk of transmission to sex partners. For behaviorally infected adolescents, support services will help them to successfully integrate their diagnosis and connect to needed services and sources of support.

*Ambulatory Outpatient HIV Medical care* that is culturally competent must be available regardless of a client's ability to pay. *Medical Case Management* must be closely integrated to assure access to eligible benefits and programs. *Treatment adherence services* are critically needed for a significant number of HIV infected children and youth. Innovative approaches continue to be developed and implemented for this challenging group of clients. They must survive their adolescent developmental hurdles in order to take more mature control of their health and treatment. A *Transitions Program* must be in place to facilitate the transfer from a pediatric care environment to an adult setting.

c) The State of Maryland Part D Network has been a uniquely successful collaboration of all key providers of pediatric, adolescent, and women's HIV care in our state. This longterm collaboration has built true working relationships among the agencies involved.

Similar to our hospital, the University of Maryland offers an array of child and youth centered medical and support services. We work closely with the care teams at University to assure coordination of efforts and open access to clients at the location of their choice.

The Moore Clinic provides services for adult clients and we are developing a transition program with them for our clients.

The Johns Hopkins Women's Health Program provides specialty gynecologic and prenatal care for our HIV positive adolescent and young adult women. The Johns Hopkins HALO program provides obstetric care for HIV positive pregnant women; we collaborate very closely with this program as several of our female adolescents and young women have become parents.

There are a wide variety of services available to HIV-positive youth in Baltimore, including social, career, and educational services, but no organization that bridges youth to those services. If the youth are not ready or able to seek them out on their own, these resources go unused by this population. The Medical and Non-Medical Case Management Programs will provide active and passive referrals to services such as those provided by the Light and Wellness Center, Dept of Social Services, Project PLASE, AIRS housing, Baltimore City Career Centers, as well as others.

d) Our case managers and social workers keep up to date on eligibility for Federal, State, and local programs providing health care coverage, income, and direct services. Client eligibility is assessed and documented at least every 6 months. Our staff members work directly with clients to complete applications and gather supporting documents for any benefits for which they are eligible. Patient Service Coordinators query the EVS system for each clinic visit. This assures that CARE Act funds are the payer of last resort.

e) Consumer involvement

Consumers are involved through the CABs, client surveys, and individual feedback and discussion. Survey results are found in the Appendix. Our youth advocate is a consumer.

The Johns Hopkins Pediatric & Adolescent HIV/AIDS Program has two Community Advisory Boards (CAB). The CAB members review programmatic issues and advise the program director on priorities for change and for new services. Both the IPC CAB and the Youth Initiative CAB meet every three months and individual discussion and feedback occur between meetings. The Youth Initiative CAB consists of adolescents and young adults infected with HIV. New program ideas are presented to both CABs to elicit suggestions during the planning and implementation phases. Program-specific feedback will be solicited from patients who utilize specific services as a means of evaluating and improving the program.

The CABs provided valuable information and feedback to the hospital leadership and architects of the new Rubenstein Child Health Building. Building design, layout, décor, flow, and access were all improved based on CAB input.

Client Satisfaction Surveys are conducted annually on site as part of the regional Ryan White program. Site-specific feedback is reviewed by the program director and shared with the CAB and program staff. Survey results are listed in the Appendix; however, we have listed below highlights from the survey:

In 2007, respondents of the Johns Hopkins Intensive Pediatric Clinic Satisfaction Survey showed overall satisfaction with the agency. Highlights include 93.9% of IPC respondents reported IPC services as **excellent** compared to 74.6% for the Central Region and 75.9% for the State. 100% of respondents were satisfied with the time spent with their service provider. 97.2% of respondents would refer a friend with similar

needs to the agency. 93.9% of respondents were satisfied with their appointment date compared to 82.9% state average. Client comments reflect the agency's goals:

"Since day one we have had excellent care. Everyone has done everything possible, give us the best."

"There really helpful and understanding the best!!"

"True wholistic[sic] care, excellent medical care, warmth, practical support."

"I have, very good doctor."

"Because I love it here, you feel at home."

Johns Hopkins IPC will continue to uphold high expectations in pursuing the highest standards of care. Results for the 2008 satisfaction survey have yet to be released.

Two focus groups were recently conducted to help plan the next phase of our treatment adherence program. One group consisted of clients who participated in our home-based Directly Observed Therapy and Training (DOTT), but were not able to achieve control of their HIV. A key finding was the chaotic nature of the focus group process itself; clients were very distractible and unable to "focus" on the topic at hand. Many of these clients reported that, although they "liked the attention" of having daily home visits from the DOTT worker, they "forgot" that she was coming or did "not hear the doorbell". A second group of clients was invited who have been successful in achieving and maintaining non-detectable viral loads for at least 5 years. Their main themes were "you can't make someone do something that they don't want to do," and they take their medication because they "wanted to live and be healthy"; "no one makes" them.

### **3. AGENCY DESCRIPTION**

a) The Pediatric & Adolescent HIV/AIDS Program of the Johns Hopkins University, a private, non-profit corporation, provides comprehensive health and social services to infants, children, youth, women, and families infected and affected by HIV/AIDS at the Johns Hopkins Hospital, a JCAHO accredited health care institution. Our mission is to assure the best quality of life for children, youth, and families living with HIV by providing state-of-the-art medical care in the context of sensitive and compassionate support services without regard to ability to pay for these services. Ryan White CARE Act funding provides critical support for this mission. Our program provides services over the broad continuum of care, as measured by the breadth and diversity of services, by the location of service provision, by the technical complexity of services, and by the age and stage of disease of individual clients receiving care. Most of the services are provided directly by program staff. Consultation and referral within the Johns Hopkins Children's Center and within the community are important links in the continuum of care.

The Johns Hopkins Pediatric & Adolescent HIV/AIDS program began in 1985 when the first child with HIV infection was identified and cared for in the Pediatric Primary Care Program of the Johns Hopkins Children's Center. The extensive and complex medical, social, and emotional needs of this child and her family crystallized the need for a comprehensive, coordinated program for children and families affected by HIV/AIDS in the Baltimore area. The Pediatric & Adolescent HIV/AIDS Program has grown in size and expanded in scope over the past 24 years in response to the needs of our community's children, youth, and their families. The clinical care portion of the program is the Intensive Primary Care Clinic (IPC), which provides intensive services and support using the primary health care, case management, and outreach models of service provision. Medical and social needs are assessed and met along the continuum of care ranging from inpatient tertiary care through outpatient ambulatory care to home and school based care by the core continuity IPC team providers who coordinate with providers of special services as needed. IPC has been successful in maintaining funding support, continuity of team members, and achievement of program goals throughout the last two decades. Client satisfaction surveys and site visits routinely rate IPC services highly (see Appendix).

The Intensive Primary Care Clinic (IPC) is located in the new Rubenstein Child Health Building on North Wolfe Street adjacent to Johns Hopkins Hospital. This new facility supports the integration of HIV care with age appropriate routine health care for patients from birth through 24 years of age. The Harriet Lane Clinic facility consists of registration, a child waiting/playroom area, an adolescent health suite with adolescent waiting area and health education center, a safety education center, a treatment procedure room, medical records area, and exam rooms. Patient flow has been redesigned to be more patient-centered, so that each patient is given an exam room and all the clinical services come to the client. Nursing triage, provider visits, immunizations, phlebotomy, psychosocial and risk reduction counseling all take place in the client's own room. All exam rooms are equipped for gynecologic exams. A CLIA and JCAHO certified 'near patient testing' facility is located on site for rapid performance of urinalyses, urine pregnancy tests, and STD screening (gram stains, wet preps, and KOH preps). Office space is located in the clinic area for nurse practitioners, nurse case managers, social workers, and child life specialists. Physician faculty offices are located one floor above the clinic for easy access.

b) The IPC Clinic serves the Baltimore EMA, the State of Maryland, the Mid-Atlantic Region, and provides international consultation. As shown in the Map of Service Area in the Appendix, our clients come from the neighborhoods in our region with the highest rates of HIV and AIDS.

HIV specialty care, including early diagnosis, antiretroviral therapy, OI prophylaxis, monitoring of viral load, CD4 count, medication side effects, and clinical disease progression, and access to clinical trials, is integrated with routine care. Routine care for infants and young children includes well child care and immunizations. Adolescents receive screening and treatment for sexually transmitted diseases and alcohol and substance abuse, reproductive health care including pelvic exams with pap smears for

young women, and contraceptive services, such as oral contraceptives, condoms, and depo-provera.

Social work services are a core part of the evaluation and management of each client. Our social workers complete a psychosocial assessment for all initial patient visits and meet with patients and their parents/caregivers who are experiencing significant psychosocial problems.

Case management and care coordination is provided on site for eligible patients. An intensive adherence program is now in place, providing pill swallowing training, adherence supplies such as pill sorter boxes, pill cutters, timer watches, and medication charts. We designed and conduct an annual weekend therapeutic retreat camp for our patients. Themes for the retreats have included medication adherence, personal wellness, and transitioning to adult responsibilities. Individual and peer group counseling is provided on site by our child life specialist, youth advocate, and social workers.

Outreach services engage new clients into care and re-engage clients who have missed appointments. Mental health consultation and treatment is provided on site for both children and adults by our psychiatrist. Substance use assessment and referral is provided on site by a specialist in adolescent addiction medicine who is certified to prescribe buprenorphine. Preventive oral health services are provided on site, with access to restorative services at the dentist's office on Charles Street.

The IPC staff consists of a pediatrician/director, adolescent medicine specialists, pediatric and adult infectious disease specialists, two pediatric nurse practitioners, two nurse case managers, two social workers, a part-time psychiatrist, a child life specialist, a youth advocate, and an outreach worker. This team functions in an interdisciplinary way to provide the most comprehensive and coordinated health and support services possible. The team is sensitive to cultural issues with regard to age, gender, race/ethnicity, childbearing decision-making, sexual orientation, and history of substance abuse. The team is comprised of members who reflect the diversity of the clients we serve: women and men; birth parent, adoptive parent, and grandparent; gay/lesbian and straight; African American and Caucasian.

Our program currently provides a full range of HIV services directly or through linkages with other providers. Almost all the operating budget comes from grants.

Current services delivered to persons living with HIV/AIDS include the following:

*Ambulatory Primary Medical Care Services (1985)*, including:

1. Infant therapies to prevent mother to child transmission of HIV (PMTCT)
2. Pediatric and adolescent HIV diagnostic counseling and testing
3. Comprehensive pediatric and adolescent HIV evaluation
4. Pediatric and adolescent HIV specific therapies (antiretroviral)
5. Pediatric and adolescent prevention therapies (opportunistic infections)

6. Periodic monitoring of disease progression and treatment outcomes (CD4, viral load, resistance testing)
7. Pediatric and adolescent health maintenance care
8. Pediatric and adolescent nutritional screening and counseling
9. Pediatric and adolescent acute illness and injury care
10. 24 hour on call for pediatric and adolescent concerns
11. Adolescent screening, diagnosis, and treatment of sexually transmitted infections
12. Adolescent family planning services
13. Adolescent screening, assessment, and referral for substance abuse treatment
14. Pediatric and adolescent screening and referral for mental health services
15. Pediatric and adolescent adherence counseling

*Inpatient Care (1985)* for pediatric and adolescent patients

*Social Work Services (1988)*, including:

1. Psychosocial screening and assessment
2. Supportive counseling
3. Crisis intervention
4. Child abuse and neglect evaluation and referral
5. Caretaker support group
6. Referral of adult family members to medical care
7. Referral of adult family members for financial and housing assistance
8. Permanency planning

*Child Life Services (1993)*, including:

1. Developmentally appropriate psychological preparation and support for medical care interventions
2. Support for HIV disclosure
3. Teaching about HIV and medications
4. Peer support groups and social gatherings
5. Therapeutic camping programs

*Case Management (1990)* for those without Medical Assistance

1. Intake and assessment
2. Care plan development in collaboration with client
3. Monitoring of goals
4. Referrals to needed services

*Care Coordination (1990)* for those with Medical Assistance, including:

1. Referral of eligible patients to the REM Program
2. Linkage with REM case managers
3. Referrals for home care services
4. Prescription refills to assure adherence

*Mental Health Services (1997)*, including:

1. Psychiatric evaluation, diagnosis, and treatment planning

2. Psychotherapy
3. Pharmacotherapy and monitoring
4. Family therapy

*Substance Abuse Assessment and Intervention Services (1997)*, including:

1. Assessment by interdisciplinary substance abuse team
2. Intervention by substance abuse counselor
3. Referral for inpatient treatment
4. Support groups for children and youth of substance abusing parents

*Adherence Services (1999)*, including:

1. Adherence assessment at each visit
2. Collaborative treatment planning with client and family
3. Specific medication adherence strategies and supplies
4. Referral for intensive outpatient behavioral psychology as needed
5. Referral for intensive inpatient adherence rehabilitation as needed
6. Intensive home-based adherence support
7. Directly observed therapy

*Buddy Program (2000)*, including:

1. One-to-one relationships between interested clients and volunteer medical students
2. Monthly group social or recreational activities
3. Individual mentoring regarding peers, school, career

*Outreach Services (2001)*, including:

1. Community-based HIV counseling, testing, and referral
2. Outreach for missed appointments
3. Partner notification of exposure to HIV and other sexually transmitted infections

*Legal Services (2003)*, including:

1. Assistance with standby guardianship and health care proxy
2. Legal advocacy

*Oral Health Services (2005)*, including:

1. Complete dental examination
2. Teeth cleaning
3. Basic restorative dental procedures

*Transitions Program from Youth to Adult (2006)*, including:

1. Anticipatory guidance regarding future transfer of care
2. "Med-Peds" trained physicians as primary providers
3. Assist clients in identifying adult clinic
4. Practice self-efficacy skills

The JHU Pediatric & Adolescent HIV/AIDS Program has received continuous funding from Ryan White Part D (originally Pediatric AIDS Demonstration Project, then Ryan White Title IV) since 1990 to sustain an innovative model of interdisciplinary family-centered care that integrates traditional medical care with enhanced support services for the entire age range from birth through age 24 years. State General funds increased the range of psychosocial support services we could provide for this population. Ryan White Part D Youth Initiative funding expanded our scope to better serve adolescents and young adults living with HIV.

This application requests continued funding from these three funding streams in order to maintain our current level of service to the community and to further innovate our programs in response to the changing needs of our clients. The overall focus of these integrated services is to promote physical and emotional health in this vulnerable population of young people so that they may grow to become healthy and independent adults. This request complements current funding for our program from Ryan White Parts A and B.

c) The Pediatric & Adolescent HIV/AIDS Program serves the WICY population of children, youth, and families living with HIV/AIDS. Any HIV-infected client in the pediatric/adolescent age group from birth through 24 years of age is eligible to receive services in the Program regardless of demographic or socioeconomic descriptors. The majority of our patients are from low-income African-American families living in the Baltimore metropolitan area who receive Medical Assistance. We are actively reaching out to the African-American MSM and transgender communities with significant increase in the number of individuals engaged in care. The rate of substance use and abuse is high within our adolescent and youth population (estimate two thirds). Our newest clients are older youth who no longer live with their family of origin. Some are homeless. Many participate in risky sexual behaviors and use alcohol and other drugs. Most are unemployed and uninsured. The clinic serves youth of all sexual orientations including MSM, WSW, and those who are transgender.

The target populations for this proposal cluster into the following groups:

- Youth (13-24) who were born with HIV and have survived into adolescence and young adulthood
- Young men (13-24) who acquired HIV through sex with other men
- Young women of childbearing age (13-24) who acquired HIV through sex with older men
- Young HIV-positive mothers (13-24) and their children
- Children (2-12) born with HIV
- Infants (0-2) born to HIV-positive mothers
- Families (self-defined) and caregivers of all of the above groups
- Youth who become homeless
- Youth who become incarcerated or are newly released

Johns Hopkins IPC Clinic	1998	2000	2002	2004	2006	2008
<b>HIV-infected patients (0-24 years)</b>	119	141	152	172	194	202
Perinatal	116	128	131	128	139	156
Transfusion	2	2	2	2	4	2
Hemophilia	1	1	1	1	1	0
Heterosexual		8	16	22	23	25
Men sex with men		1	1	15	24	18
Injecting drug use		1	1	4	3	1
0-23 months old	11	5	2	2	1	3
2-12 years old	98	97	70	53	42	35
13-24 years old	10	39	80	117	151	164

A total of 324 clients were served in our clinic-based and outreach programs in CY 2008. Two hundred two have confirmed HIV infection and are enrolled for HIV medical care. Males

represent 46%, females 53%, and transgender individuals 1% of the total. Household income is below the Federal poverty level for 83% of clients; 98% fall below 300% of the Federal poverty level. Sixty-three percent are insured through Medicaid, 2% Medicare, and 19% are uninsured. Of the total population, 83% are Black, 7% are White, and 2% are Hispanic.

In contrast to common belief, there are more children and adolescents living with HIV in Maryland than ever before. Although the rate of new infections due to perinatal transmission has dropped significantly over the past decade, there has been a recent increase in newborns identified with confirmed HIV infection, an alarming trend. In addition, the increased survival of these children added to the increasing rate of new infections in adolescents has caused a near **doubling in the number of clients** enrolled in our program over the past ten years. (Table)

The number of clients 13 years and older has **increased 16-fold** during this same time period. Our pediatric providers are integrated in the same clinic team with the adolescent medicine providers to assure that we are meeting the needs of this emerging population. The trends in age distribution and risk category over time of the Johns Hopkins pediatric and adolescent client population are listed in the table above.

Currently in 2008, we care for 44 youth who acquired HIV through “adult” risk behaviors. Twenty are young women with heterosexual exposure; thirteen of the twenty are mothers. Our youth with perinatal HIV are also sexually active and bearing children. Eight women and four men have already become parents. This dramatic rise in the number of young people of childbearing age engaging in unprotected heterosexual activity demands comprehensive adolescent services with close links to the prenatal care program for their health and the pediatric care program for their children. The challenge of medication adherence is significant in adolescents. When the adolescent is pregnant, her adherence becomes all the more critical to prevent HIV infection in her newborn child. We are redoubling our outreach and support services to promote safer sex practices and family planning. We are reinforcing our efforts to incorporate Prevention for Positives into our routine clinical services.

Eighteen youth are African-American MSM and 4 report heterosexual risk exposure. This also represents a dramatic rise in young men and sexual minority youth in our population. We are responding with specific outreach activities and participation in the city wide Community Advisory Board for the Part D Youth Initiative. Our newest clients are older youth who no longer live with their family of origin. Some are homeless. Many participate in risky sexual behaviors and use alcohol and other drugs. Most are unemployed and uninsured. Adolescents and young adults are most successful engaging in care that is culturally and developmentally appropriate. We need to expand the capacity to provide one-stop coordinated HIV services for this underserved group. We have used all of our clinic-based strategies to promote adherence with some success. However, there are youth who need the structure and supervision of directly observed therapy to get them on the road to improved health and self-efficacy. Young gay men and transgender youth are being successfully engaged into HIV primary care in the IPC Clinic. As they consider initiating HAART, they need adherence support that is culturally sensitive.

Most of our child clients born with HIV/AIDS are becoming adolescents and young adults with all the challenges of that rapidly changing time of life. It is well known that some adolescents with chronic illness become non-adherent to their medical regimens. Our clinical experience has repeatedly shown us that parents and guardians delegate responsibility for medication almost entirely to the child (including reminding the parent that they need a refill at the pharmacy) by the age of 12 years. This seems intended to be a positive way of showing trust and pride in the child's growing maturity. However, the children show us that they need increased adult supervision and support at this age that is tailored to their emerging independence. In several families, the conflicts over medication have spread to conflicts about behavior, relationships, and safety resulting in the child being extruded from the home into foster care or an institution.

d) The Pediatric & Adolescent HIV/AIDS Program functions administratively and academically within the Division of General Pediatrics and Adolescent Medicine in the Department of Pediatrics of the Johns Hopkins University School of Medicine. The Johns Hopkins University is a private, non-profit corporation. Dr. Nancy Hutton has directed the IPC Program since 1985, overseeing program management and clinical care. Adowa Weaver is the Program Manager for Ryan White in the Department of Pediatrics and is supervised by the General Pediatrics Administrative Manager and Dr. Hutton.

Johns Hopkins University has extensive experience with fiscal management of grants and contracts.

The Financial Systems Administration Office of Johns Hopkins University is responsible for all technology implementation in the Controller's Office. This includes development and maintenance of LAN and Web-based information systems. This includes Hyperion Reporting, the E210 Electronic Timekeeping System and the Controller's Office

Website. Internally this staff provides support for all departmental network and desktop systems.

The Research Accounting Office reports to the Director of Cost Analysis in the Controller's Office. This office is responsible for sponsored account activities including preparation of Financial Status Reports, invoicing for cost reimbursable grants and contracts, approval of other budget and grant awards.

The Division of General Pediatrics and Adolescent Medicine has a fulltime administrative manager who provides pre and post award fiscal management. The IPC Program has a fulltime Program Manager under the supervision of the Division administrative manager. Ms. Weaver is responsible for all communication with the Ryan White Administrative Agents and funders, budget preparation, expense monitoring, and preparation of program reports.

Johns Hopkins Medicine Center for Information Services (JHMCIS) provides computing and network services for the Hospital and the Department of Pediatrics. The EPIC system records patient appointments, visit registration, and billing information. We have invested significant time and effort to install and maintain CAREWare, to train our service staff in direct data entry, and to customize reports in order to meet the multiple reporting requirements of CARE Act funding. This software permits electronic reporting of client-level data. The program manager maintains this confidential database of unduplicated clients receiving Ryan White funded services using the Unique Reporting Number (URN).

e) The recent upgrade of CAREWare now supports the electronic data reporting to the AIDS Administration. Our agency is in compliance with reporting requirements.

f) IPC team members participate in networks, task forces, and planning bodies, such as the State of Maryland Ryan White Part D Network, the State of Maryland Part B Consortium, the Greater Baltimore HIV Health Services Planning Council, and the state HIV/AIDS Advisory Group for Maryland Medicaid Reform.

The IPC Program offers a full continuum of health and support services on-site to infants, children, youth, women, and families infected and affected by HIV/AIDS. We collaborate with community agencies that provide services needed by our clients. The continuum of child- and youth-centered services spans location, level of complexity or acuity, type of service, and type of provider. We have found that the most effective way to engage high risk and disenfranchised clients is to provide a welcoming, respectful, responsive program that meets their needs in "one stop" as much as possible.

Community agencies refer clients to us through the IPC nurse case managers at (410) 955-7984 and (410) 502-2316 to assure timely and complete access to needed services. Referrals are accepted from any source, including hospitals (newborn nurseries, pediatric inpatient units, and hospital clinics), free-standing clinics, HMOs, emergency rooms, health departments, community outreach programs, community

based practices, shelters, social service agencies, CBOs, word of mouth, and self referrals.

Outgoing referrals are made through the nurse case managers. They track that appointments are made and kept, that we receive reports from consultants and other agencies as appropriate, and that these documents are reviewed and filed in the client's chart.

We collaborate most actively with providers of HIV specific child-centered services, youth-centered services, and providers of women-centered services. We also collaborate actively with providers of other services needed by children and youth, although they are not solely HIV service providers and do not receive funding through the Ryan White CARE Act. Examples of these organizations include home health agencies, durable medical equipment companies, nursing agencies, schools, Baltimore City Schools CHIP program, Department of Social Services, Juvenile Services, and the courts. The continuum of client and family-centered services includes direct support services for HIV positive mothers (both teens and adults), collaboration with the HIV Prenatal Program and Women's Health Program, and referral linkages with adult HIV medical providers, substance abuse counseling and treatment services. All services and linkages are ongoing, with continuity through time a key characteristic.

The Pediatric & Adolescent HIV/AIDS Program has formal linkages with many HIV service providers in the Baltimore EMA to whom we refer clients and from whom we accept referrals. Our current signed Ryan White Linkage Letters and Memoranda of Agreement are found in the Appendix. However, we do not limit our linkages to these providers.

#### **4. PROJECT/SERVICE DESIGN AND IMPLEMENTATION**

##### **a.) Project Overview**

*Project goals and how project strives to meet the needs of target population:*

Johns Hopkins Pediatric & Adolescent HIV program's goal is to provide expert comprehensive health and social services to infants, children, youth, women, and families infected and affected by HIV/AIDS. Our program strives to fill the gaps in care for the growing population of HIV- infected clients in the Baltimore EMA. This unique population requires a comprehensive approach that is competent in providing care that is developmentally appropriate and sensitive to issues of age, gender, sexual orientation, and race/ethnicity. The Johns Hopkins Pediatric and Adolescent HIV/AIDS Program based in the IPC Clinic has become the premier program in the EMA servicing this unique population. We repeatedly observe that coordinated, comprehensive; one-stop care with a continuity team of committed and skilled professionals provides the best quality of care, health outcomes, and client satisfaction. For this reason, we strive to meet the client needs within the IPC Clinic whenever possible, expanding and changing the program in response to changes in our local epidemic. We currently witness our aging population struggle with medication and care adherence. We have

also seen a strong client need for increased knowledge and improved life skills to assist with the successful transition to independence and adult medical care. Our goal is to expand our comprehensive program with a special concentration on improving treatment adherence for this unique population.

The Johns Hopkins Intensive Primary Care Clinic (IPC) is unique within the pediatric and adolescent HIV treatment community in the United States. From its inception, IPC has provided prospective, continuous care for its clients, integrating HIV specialty care with primary health care. IPC is dynamic, tracking shifts in the client population and adding and updating services in response. Specifically, IPC integrated the care of child (0-12 years) and youth populations (13-24 years), providing longterm continuity for HIV positive children growing into adolescence and young adulthood, HIV expertise in a familiar environment for adolescents newly identified with HIV, and a safe and welcoming full service clinic for sexual minority youth with HIV. *In contrast to many centers, we do not have separate pediatric and adolescent clinics or separate clinics for adolescents with perinatally-acquired HIV vs. behaviorally-acquired HIV.* This provides economy of scale and assures both breadth and depth of expertise to meet the varied needs of our clients.

Our strong commitment to excellent patient care keeps us at the cutting edge of new HIV treatments, continually evaluating and improving our services. For example, IPC was one of the first pediatric programs in the US to prescribe protease inhibitor therapy for children. This was a direct result of the strong partnership between the IPC director and the parents of pediatric patients in care. In 1996, adults were using this new therapy with great success, yet their children were growing sicker and more were dying each year. Parents legitimately felt that if the doctors could not find a way to provide this life-saving therapy for their children, they would give them their own medicine in order to save their lives. The IPC Director worked with parents to craft a safe treatment plan based on early pediatric research findings at the NIH, allowing IPC patients access to this treatment a full year prior to its availability within clinical trials.

We take pride in not maintaining a waiting list because we do not believe new clients should wait to initiate care! We provide service as soon as a client contacts us. First medical appointments have been offered within 24 hours of referral when appropriate. This strategy has facilitated engaging newly identified youth immediately into supportive care within the IPC team and early access to medical evaluation and care.

#### *Projects role within the Maryland Part D Network:*

The Johns Hopkins Pediatric & Adolescent HIV/AIDS Program has been a part of the Maryland Part D Network since it began as the Pediatric AIDS Demonstration Project in 1990. We are one of only two providers in Baltimore City who provide comprehensive integrated medical and social services for HIV/AIDS infected and affected clients (birth through age 24 years): infants, children, youth, women and families. Our interdisciplinary IPC Clinic provides primary medical care, medical case management and care coordination, social work services, child life services, mental health services,

substance abuse assessment and intervention, adherence services, legal services and a buddy program. We have a strong working relationship with other providers in the Maryland Part D Network and work very effectively together to collaborate and coordinate services. We accept pediatric and adolescent referrals from our Part D colleagues; at the same time we utilize our strong connections with these other providers to refer our clients for identified services such as daycare, support groups, prenatal care, and adult primary and/or specialty medical care.

*How agency will inform, engage and retain clients in services:*

Our clinic engages child, youth adolescents and young adults into care through a variety of means: referrals from community HIV providers and counseling /testing sites; Baltimore City and local county Health Departments, school health suites, hospital in-patient and emergency room settings, medical providers, outreach efforts and self referrals. JHU Pediatrics is very proud that current adolescent clients have referred their HIV positive and affected friends and partners for care at the IPC Clinic. This is taken as a huge compliment and a measure of our program's success when our youth trust the IPC Clinic and staff enough to refer a friend. These new and existing clients are successfully retained in medical care due to staff diligence and commitment to providing the best medical and supportive services to our clinic youth and families. Clients appreciate the convenience of being able to access many services in one clinic location. Clients also appreciate the intimate nature of our clinic and the individualized attention, treatment plans and support received from all members of our interdisciplinary team. This strong rapport and trust built between staff and the client greatly assists with clients' adherence to treatment and recommended referrals.

The IPC Clinic is located within the Johns Hopkins Hospital Harriet Lane Primary Care Clinic where services are provided to patients with and without HIV. This has facilitated acceptance of and access to services by HIV positive youth, adolescents and young adults. The fact that services provided at this site are not segregated by the HIV diagnosis has repeatedly been cited by our patients as the reason they chose to come to this facility for care. An emphasis on assessing high risk behaviors and assisting youth & families to deal with the various issues of adolescence is central to the program. Teens identified with special needs are connected with appropriate services and case management. Staff members represent diverse backgrounds & experiences, complementing one another as part of a vibrant interdisciplinary team. Common among all staff members are their excellent clinical skills with adolescents, their ability to build rapport with youth, and to communicate with them credibly.

Strategies that we employ to make and keep our services accessible to emerging populations are the following:

Youth, child and family friendly environment: Infant and child waiting area is decorated with the children's own artwork; supervised arts and crafts in waiting area; children's videos; children's books; adult supervision of children permits parents to meet privately with pediatric or adult care providers. Adolescent Health Suite provides a separate waiting area for youth and young adults with a health education resource center

containing three computers with internet access and age appropriate educational materials such as pamphlets, posters, and bulletins boards.

Diverse program staff: The team is comprised of members who reflect the diversity of the clients we serve: women and men; birth parent, adoptive parent, and grandparent; gay/lesbian and straight; African American and Caucasian.

Outreach workers: IPC has a youth advocate and an outreach worker who are trained to work with adolescents and young adults to promote adherence to care and to engage new youth into care. These two outreach workers also participate in school and community agency HIV education sessions, as well as providing twice monthly educational sessions at the Department of Juvenile Services. The Johns Hopkins HIV Women's Health Program provides peer outreach to pregnant women and women of childbearing age, linking infants and children to primary medical care in the IPC Clinic. They also facilitate the enrollment of pregnant HIV positive adolescent women from IPC into the Halo prenatal program.

Multilingual service: Johns Hopkins has an on-site translator service to assist in the communication between medical providers and their patients. One of our HIV Specialists is multilingual (English, Spanish, French, Creole). Our psychiatrist is multilingual (English, French, Spanish).

Transportation assistance: We provide bus tokens, parking coupons and cab vouchers for patient visits under our Ryan White Part D grants. Referrals to Ryan White funded Moveable Feast transportation is also frequently utilized.

Client feedback is sought and utilized to improve services: This engenders a sense of collegiality and collaboration.

*Verification of Ryan White Part D Eligibility and needs assessment process/ knowledge of available benefits for clients living with HIV:*

All clients participate in an intake assessment to determine eligibility for Ryan White services, entitlements and other services. 98% of clients enrolled in the IPC clinic have annual incomes below 300% of the federal poverty level, meeting the income eligibility for Ryan White services. Staff members assist clients in applying for Medicaid, Medicare, PAC, and MADAP. Insurance status is updated every six months according to Ryan White Standards of Care.

JHU IPC Program completes Ryan White Eligibility forms with 100% of our clients every six months to confirm that Ryan White is utilized as the payer of last resort. Our agency has improved greatly in our ability to collect needed documentation (income and verification of residency in the Baltimore EMA) to confirm Ryan White Eligibility. The social workers and the nurse case managers routinely audit the charts, prior to scheduled clinic visits, to confirm that Ryan White Eligibility is confirmed. Additionally, each client is personally known, and followed, by one consistent social worker and case manager; this connection with the clients also ensures that Ryan White Part D funds are used only for our HIV infected infants, children, youth, adolescents, young adults and their families.

Our interdisciplinary team works very hard to offer clients benefits and resources available to people living with HIV. All clients receive a thorough psycho-social assessment yearly by our two clinic social workers and updated needs assessments during routine clinic visits with the primary care provider. The case managers also routinely meet face-to-face with the clients to assess for needs and coordinate referrals. Our social workers and case managers are very knowledgeable regarding the many benefits and resources for our clients living with HIV. Contacts at various agencies serving HIV infected and affected clients, especially Part D Network providers, have been established over the years and are frequently utilized to help our clients. IPC team members, including our Youth Advocate and Outreach staff, attend meetings and trainings where new resources are learned and connections are formed. Team members share these newly learned resources and benefits at our weekly IPC team meeting.

*Referral relationships, procedures for assessing client's needs for services, and procedures for making and tracking referrals:*

Services needed by the client, which are not provided on site, will be referred to an appropriate provider. The Clinic and the case managers have established many referral and linkage relationships.

Commonly utilized agency referrals include:

- Adult care providers - Johns Hopkins Moore Clinic and other specialty clinics, Johns Hopkins HIV Women's Health Program, Johns Hopkins HALO Clinic, Total Health Care, Park West Hidden Gardens, Sinai, University of Maryland, Chase Brexton Clinic, Bayview Center for Addiction and Pregnancy (CAP), Baltimore City and local county Health Departments
- Addiction Treatment Services – CAP, Mountain Manor, Comprehensive Women's Center
- Dental Care – University of Maryland School of Dentistry, Community dentist
- Ryan White transportation resources such as Moveable Feast
- Outreach and supportive services such as STAR (Sisters Together and Reaching), WAR (Women Accepting Responsibilities), Light Health and Wellness, Martin Luther King Jr. Early Head Start, Department of Social Services
- HIV Case Management – REM Case Managers, Local Health Department Case Managers
- Emergency Assistance – AIDS Action Baltimore, Total Health Care
- Housing Services – AIRS Housing, Project Phase
- Home Health Care – Pediatrics at Home, Pharmequip

Need for referrals are assessed routinely during clinic visits by both the case management team and the medical providers. New referral needs are often identified during initial care plan development as well as during subsequent care plan updates. Outgoing referrals are made through the social workers and nurse case managers and

documented in both the patient's electronic patient record and CAREWare. Case managers track that appointments are made and kept, that the clinic receives reports from consultants and other agencies as appropriate, and that these documents are reviewed and filed in the client's chart.

*Cultural and linguistic competence:*

Translation services through the Johns Hopkins Hospital are available to all of our clinic patients for appointments and phone interactions, if needed. Additionally, we have two physicians who are multilingual. Respect for clients as individuals in the context of their families and communities is a core value of our Program. Several staff are members of affected communities. Staff members represent the diversity of the clients we serve. Clients consistently report high satisfaction with the staff and services in annual surveys. This past year our clinic has provided HIV care to 3 transgender clients. To assure the best quality of care for this small, but increasing group, staff was provided a training regarding best care practice for transgender youth. Team members are encouraged to attend trainings and conferences to expand their knowledge regarding HIV, medications, adherence techniques, adolescent populations, cultural competency, or other topics of interest.

**b. Requested Service Categories**

**Outpatient / Ambulatory Health Services**

*Proposed activities / interventions, implementation, clients served, timeline:*

The Johns Hopkins Pediatric & Adolescent HIV/AIDS Program utilizes a comprehensive integrated clinical practice model, allowing us to maintain continuity of HIV provider while expanding the care team to include experts in adolescent medicine, reproductive health, sexually transmitted infections, risk reduction and secondary prevention counseling, community outreach to sexual partners to provide HIV counseling, testing, and referral, substance use disorders, mental health problems, and legal issues. Each client is assigned a primary care provider (a pediatric/adolescent nurse practitioner or physician), a case manager, and a social worker. Primary care providers are trained in general pediatrics and adolescent medicine and in HIV care and treatment. Clients are seen by appointment for routine HIV and health maintenance care by their primary care provider. Acute illness visits are provided on site by the General Pediatrics team in consultation with the IPC team. Inpatient admissions are covered by the General Pediatrics team with IPC consultation. All care is provided consistent with local and national Standards of Care and documented in the Electronic Patient Record.

Specific activities and responsibilities of the medical care providers include:

- Infant therapies to prevent mother to child transmission of HIV (PMTCT)
- Pediatric and adolescent HIV diagnostic counseling and testing
- Comprehensive pediatric and adolescent HIV evaluation
- Pediatric and adolescent HIV specific therapies (antiretroviral)

- Discussion of potential medication side effects and steps to manage them with all clients for whom medications are prescribed
- Pediatric and adolescent prevention therapies (opportunistic infections)
- Periodic monitoring of disease progression and treatment outcomes (CD4, viral load, resistance testing)
- Pediatric and adolescent health maintenance care
- Pediatric and adolescent nutritional screening and counseling
- Pediatric and adolescent acute illness and injury care
- 24 hour on call for pediatric and adolescent concerns
- Adolescent screening, diagnosis, and treatment of sexually transmitted infections
- Adolescent family planning services
- Adolescent screening, assessment, and referral for substance abuse treatment
- Pediatric and adolescent screening and referral for mental health services
- Pediatric and adolescent adherence counseling

Our program targets the WICY (women, infants, children, and youth) population and is uniquely qualified to serve the *special population* of youth 13-24 years old, who make up 67% of the uninsured primary medical care clients served through November 30, 2008. We also serve children from birth to age 12 years. The remaining 33% of our uninsured clients are in this younger age group, emphasizing the continued need for Ryan White support for this age group. Ryan White funding allows us to serve this younger population by assessing eligibility and need, enrolling or re-enrolling them in Medicaid if eligible, or provide ongoing HIV primary medical care if not eligible.

Continuation of Ryan White Part D, Part D Youth, and State General funding is requested in order to maintain the current level of *Ambulatory Outpatient Medical Care Services* provided by the Johns Hopkins IPC Clinic to HIV exposed and infected clients from birth to age 24 years seeking care in the State of Maryland. The following services are already in place in the Intensive Primary Care (IPC) program located in the Harriet Lane clinic at Johns Hopkins. Specific services are described below, with numbers of uninsured and underinsured clients who could receive care for those services.

The implementation date and duration of services will be throughout the grant year (July 1, 2009 – June 30, 2010).

- Prevention of Mother to Child Transmission of HIV (PMTCT)

IPC collaborates actively with the Johns Hopkins HIV Women's Health Program and Halo Prenatal Clinic to assure uninterrupted antiretroviral treatment for infants born to HIV positive mothers based on current care guidelines. Pediatric HIV Specialists provide consultation to the Neonatal ICU to tailor PMTCT recommendations for premature or critically ill HIV-exposed newborns.

Number of clients: 25  
Implementation date: 7/1/2009

- Pediatric and adolescent HIV diagnostic counseling and testing

HIV counseling and voluntary testing are already provided as part of routine health care in the Harriet Lane Clinic for (a) infants and children born to HIV infected mothers, (b) adolescents who are sexually active, and (c) adolescents who inject drugs. Confirmatory testing will be provided for newly diagnosed Ryan White clients entering care. Counseling to prevent the spread of HIV to others is provided for all clients.

Number of clients: 75  
Implementation date: 7/1/2009

- Comprehensive pediatric and adolescent HIV evaluation

HIV Specialists provide comprehensive evaluation for all new Ryan White clients. Comprehensive reevaluation is conducted as clinically indicated, at least annually. This evaluation is tailored to the age and developmental stage of the client. At a minimum, the initial evaluation includes complete medical history, complete physical exam, and laboratory studies (CBC, chemistry profile, lipid profile, HIV viral load, CD4 count), and psychosocial assessment. In adolescent and young adult patients, screening by interview and appropriate testing is conducted to identify sexually transmitted infections, alcohol and other substance abuse, and mental health disorders.

Number of clients: 200  
Implementation date: 7/1/2009

- Pediatric and adolescent HIV specific therapies (antiretroviral)

HIV Specialists assess the medical indications for antiretroviral therapy for each client according to published treatment guidelines ([aidsinfo.nih.gov](http://aidsinfo.nih.gov)). Readiness to begin and maintain adherence to combination antiretrovirals is assessed and optimized prior to recommending therapy. Prescription coverage is arranged prior to initiating therapy.

Antiretroviral treatment is planned collaboratively between the HIV specialist and the client, often with the support of other members of the client's family and other members of the interdisciplinary team. Review of medication options, pill burden, dosing schedule, and side effect profile occurs in order for the client to make an informed choice among recommended treatment options.

Number of clients: 200  
Implementation date: 7/1/2009

- Pediatric and adolescent prevention therapies (opportunistic infections)

All recommended immunizations are provided according to age appropriate guidelines for all clients attending the Harriet Lane Clinic. The clinic is a VFC participant so that

uninsured clients are not charged for vaccines. Additional vaccines recommended for HIV infected clients (influenza, pneumococcal) are also provided under the VFC program. Clients with severe immunodeficiency, defined as category 3 CD4 count or percent, do not receive live viral vaccines such as varicella or measles due to risk of disseminated disease.

HIV specialists assess the client's risk of opportunistic infections according to CD4 category and baseline serologic testing. Primary and secondary prevention is prescribed according to published guidelines. Ophthalmologic screening is performed as indicated in the guidelines.

Number of clients: 200  
Implementation date: 7/1/2009

- Access to perinatal, pediatric, and adolescent AIDS Clinical Trials

The interdisciplinary team maintains active collaboration with local clinical research groups, such as the International Maternal, Pediatric, and Adolescent AIDS Clinical Trials Network (IMPAACT), the Adult AIDS Clinical Trials Group (ACTG), and the Adolescent Trials Network (ATN). All clients are informed about the importance of clinical research. Specific opportunities for participation are identified and offered to clients. The interdisciplinary care team remains actively involved in their care throughout their enrollment in a clinical research protocol. There are no costs associated with participation in these research studies.

Number of clients: 200  
Implementation date: 7/1/2009

- Periodic monitoring of disease progression and treatment outcomes (CD4, viral load, resistance testing)

All HIV infected clients are seen at least quarterly for interval monitoring including interval medical, social, and mental health history, physical exam including growth parameters, laboratory studies assessing virologic response to antiretroviral therapy, maintenance or improvement in immunologic category, and incidence of medication toxicities. Medication adherence is reinforced at every visit.

Failure to suppress HIV viral load, or a rebound in viral load after suppression, prompts further evaluation of adherence and of potential viral resistance. Interventions to improve adherence are provided while resistance is evaluated. If the client harbors resistant virus, then a new regimen is designed with the client and frequent monitoring for viral suppression is conducted.

Number of clients: 200  
Implementation date: 7/1/2009

- Pediatric and adolescent health maintenance care (EPSDT)

Health maintenance care is integral to comprehensive HIV primary care and is provided for Ryan White clients at no additional charge. This care includes routine health screenings, counseling, anticipatory guidance, and recommended immunizations.

Number of clients: 200  
Implementation date: 7/1/2009

- Pediatric and adolescent nutritional screening and counseling

Assessment of weight, height, weight for height, and body mass index are performed at each evaluation and interval visit. Growth curves are plotted for trends over time. Nutritional counseling to promote growth, maintain adult weight, and reduce lipid and glucose toxicities is provided in the clinic. Consultation with a registered dietician is available as needed within the institution.

Number of clients: 200  
Implementation date: 7/1/2009

- Pediatric and adolescent acute illness and injury care

The Harriet Lane Clinic facility is open five days a week for acute care, providing continuity with the IPC interdisciplinary team on site. The Emergency Department is open 24 hours a day, 365 days a year for illness and injury care that cannot be provided in the clinic setting. IPC staff are available to Emergency Department staff during evaluation and treatment of Ryan White clients.

Number of clients: Available to all clients (ED visits are not covered RW serv)  
Implementation date: 7/1/2009

- 24 hour on call for pediatric and adolescent concerns

Faculty physicians are on call after hours for telephone consultation and referral to the Emergency Department for urgent problems. Faculty physicians provide attending coverage when clients require inpatient admission.

- Adolescent screening, diagnosis, and treatment of sexually transmitted infections

Sexually active adolescent and young adult clients (men and women) are screened for STI's at least semiannually. Diagnostic testing is performed for symptomatic concerns. Treatment is provided according to published treatment guidelines. Communicable disease reporting and partner notification are conducted through the Baltimore City Health Department.

HIV infected clients are routinely counseled regarding safer sex practices. Diagnosis of a sexually transmitted infection is a red flag that a client needs more intensive prevention counseling and support. Condoms are provided at no charge.

Number of clients: 150  
Implementation date: 7/1/2009

- Adolescent family planning services

Reproductive health services are available to all adolescent and young adult clients. Contraception methods are discussed with clients engaging in heterosexual activity. Condoms are provided without charge.

Number of clients: 150  
Implementation date: 7/1/2009

- Adolescent screening, assessment, and referral for substance abuse treatment

Substance abuse screening questions are asked at interval visits. Positive responses prompt assessment by the substance abuse team (addictions specialist physician and social worker) on site. Referral and follow-up are provided to and from alcohol and drug treatment programs.

Number of clients: 150  
Implementation date: 7/1/2009

- Pediatric and adolescent screening and referral for mental health services

Screening questions and direct observation of affect and behavior are used to identify clients in need of mental health evaluation. Referral is made to the HIV mental health team (psychiatrist and social worker) on site.

Number of clients: 200  
Implementation date: 7/1/2009

- Funding will be utilized to cover the costs of medically necessary laboratory tests and x-rays not covered by the Ryan White program.

Number of clients: 20  
Implementation date: 7/1/2009

*Evidence base / effectiveness:*

Health services are provided according to the evidence-based treatment guidelines published on line by the United States Department of Health and Human Services ([aidsinfo.nih.gov](http://aidsinfo.nih.gov)). Specific guidelines include:

- The Use of Antiretroviral Agents in Pediatric HIV infection (Dr. Hutton is a member of this national guidelines committee)
- The Use of Antiretroviral Agents in HIV-1 infected Adults and Adolescent
- Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States - July 8, 2008
- Prevention & Treatment of Opportunistic Infections in HIV Infected Adults and Adolescents

Use of these treatment guidelines within the framework of an intensive primary care (IPC) model has resulted in a remarkable track record for our patients. Despite the social and behavioral risks of our IPC client population, we have achieved impressive health outcomes, including

- o 80% survival over a twenty year period
- o 88% of clients have CD4 count greater than 200
- o 66% of clients have undetectable viral load

Balancing the individual needs of each client with currently available treatments and constantly changing treatment guidelines gives the best outcomes. We are delighted that one of our newest scheduling challenges is working around the college schedule of our 18-22 year old long term survivors with lifelong HIV. What a great reason to book an extra clinic session over the Christmas holidays!

The IPC is very aggressive in its support for adherence to care and treatment. The effectiveness of scientific breakthroughs depends completely on the ability of providers and clients to partner successfully in creating and adhering to an individualized plan of care. We recognized early in the HAART era that most virologic failure was a result of less than perfect adherence rather than drug resistance, even in patients with documented resistance. We implemented a rigorous inpatient program for children and adolescents with multi-class resistance that resulted in sustained improvements in viral load and CD4 count. We monitor clients very closely in the clinic and at home when HIV medicines are first initiated and whenever changes are made. Every member of the interdisciplinary team is part of the adherence team. Adherence support is an integral component of our Outpatient/Ambulatory Health Services.

*Timeline for implementation of new or expansion dollars:*

The Pediatric & Adolescent HIV/AIDS Program is a well established clinical program. Requested funds will support the continuation of current activities. Funded activities begin July 1, 2009.

### **Mental Health Services**

*Proposed activities / interventions, implementation, clients served, timeline:*

The goal of the IPC Clinic Mental Health Program is to assure continued access to developmentally and culturally appropriate mental health services for underinsured and uninsured children, youth, women and families living with HIV/AIDS. Mental health consultation and treatment are provided on site for both children and adults by our psychiatrist. The University of Maryland Pediatric HIV Program, a Part D Network colleague, also refers their youth and adolescent clients in need of Ryan White funded psychiatric care to Dr. Wissow at the IPC Clinic. Social work collaborates closely with the psychiatrist to provide assessment and counseling services. Ryan White Part D and State General funding is requested to continue *Mental Health Services* to accommodate the increasing number of underinsured HIV infected clients, from childhood to age 24 years, and their affected family members, access needed mental health support and services. This funding will also be used to continue our current mental health program and to add a Mindfulness-Based Stress Reduction (MBSR) program for HIV – infected and affected youth, adolescents and young adult mental health clients. Our mental health program assists with sustaining clients in care by engaging our clients in culturally sensitive mental health services; thus optimizing their mental health and functioning level and improving medical outcomes related to treatment adherence. All services meet Standards of Care as approved by the Greater Baltimore HIV Services Planning Council.

*Mental Health Services for the 12 month duration period (7/1/2009 – 6/30/2010):*  
Implementation date for all interventions will begin 7/1/2009

- The social worker will complete thorough psychosocial assessments on all IPC youth, adolescents and young adults and their family to screen for mental health conditions and refer to IPC psychiatrist when indicated.  
Number of clients served: 200
- The psychiatrist will provide psychiatric evaluation, diagnosis, and treatment planning for children and youth referred from social work and primary medical provider screening.  
Number of clients served: 20  
Number of evaluations & treatment plans formulated: 20
- The primary medical care providers will improve early detection of mental health problems by integrating routine mental health screenings with ongoing HIV primary medical care for all IPC patients using the HEADDSS screening tool.  
Number of clients served: 150  
Number of HEADDSS screens completed: 150
- The psychiatrist and social worker will provide therapeutic counseling based on the psychosocial and mental health evaluation / treatment plan.  
Number of clients served: 45  
Number of sessions (individual psychotherapy, prescription and monitoring of psychotropic medications, family therapy) provided by the psychiatrist: 25  
Number of social work sessions, under psychiatrist supervision, for individual and family counseling: 85

- The psychiatrist will provide ongoing consultation and support to HIV primary medical care providers in screening and managing common mental health problems.  
Number of weekly IPC team meetings attended  
by the psychiatrist 24
- MBSR group will be held to support the emotional development of youth, reduce chronic stress, and improve coping skills as related to mental illness and HIV  
Number of clients served: 20  
Number of MBSR sessions: 12

*Evidence based / effectiveness:*

The IPC Clinic's mental health program has significantly grown over the years. Our program has moved up a level of complexity; we are proud of our capabilities this year to successfully manage care, labs and mental health services for several youth with significant mental health, medical and psychosocial needs. The success of our mental health program is due, in part, to its physical co-location with our other Ryan White services and the close interdisciplinary teamwork in the IPC Clinic. The psychiatrist and the social worker have worked hard to develop a very efficient program where the medical providers have learned to successfully screen, refer and manage mental health conditions along with support and collaboration from the mental health team. Additionally, this year we began to offer coordinated medical and mental health care for our small, but growing, transgender population. Our small group of transgender youth has built a strong rapport with both the IPC medical and mental health providers, greatly aiding to their adherence to recommended care.

Overall, IPC Clinic wide, the clinic staff has built strong rapport with the youth. This strong rapport has aided with engaging youth in mental health care when indicated. We have found that untreated mental health issues are a barrier to effective treatment adherence. Clients who are engaged in consistent mental health care also show improved compliance with medical HIV care. Continued mental health services for our uninsured youth and young adults is very important as it improves clients adherence to care and medical outcomes, increases coping mechanisms and improves the client's outlook on living well with HIV. If mental health services were not available within our HIV primary care site, our youth would have difficulty finding youth-friendly mental health care or utilizing outside mental health agencies due to fear and stigma.

*Timeline for implementation of new or expansion dollars:*

The Johns Hopkins IPC Clinic will utilize funds as soon as they become available. The Pediatric & Adolescent HIV/AIDS Mental Health Program is an established program and requires no additional time to utilize grant funding.

**Medical Case Management (including Treatment Adherence)**

*Proposed activities / interventions, implementation, clients served, timeline:*

The goal of the medical case management program in the IPC Clinic is to facilitate uninterrupted access to a comprehensive and coordinated continuum of developmentally appropriate HIV, health, and social services for our increasing number of underinsured and uninsured children, youth, adolescents and young adults infected and affected by HIV/AIDS. The youth have a more difficult time obtaining insurance once they turn 19 years old as they are no longer eligible for MCHIP (Maryland Children's Health Insurance Plan) and must apply for Medical Assistance or obtain private / employer based insurance. Medical Assistance has been increasingly difficult to obtain for many of our youth who are not considered "disabled". Ryan White funding is very important for these youth as it allows them to remain engaged in HIV care despite their lack of insurance. Threshold and gap case management services are needed to assure that intermittently insured clients do not fall out of care. Case management services provide the valuable coordination and support needed to engage new clients in care and facilitate continuation in primary care.

Ryan White Part D and State General funding will permit the continuation and expansion of the successful JHU Pediatric & Adolescent Medical Case Management Program and enhance our program by targeting the transition and treatment adherence needs of our HIV infected adolescents and young adults. In addition to our two current nurse medical case managers, Ryan White Part D / State General funding will permit us to add a licensed social worker on our well established case management team to provide adolescent specific psychosocial assessment, counseling, and support for HIV-positive youth and young adults to promote successful treatment adherence.

Implementation date for all interventions will begin 7/1/2009 (Duration period 7/1/2009 – 6/30/2010)

- The MCM (medical case manager) will provide intake and evaluation for all uninsured and underinsured HIV positive youth, adolescents and young adults. Health insurance status and case management needs will be assessed. Care plans will be developed in collaboration with clients.  
Number of clients served: 150
- The MCM will provide ongoing case management services through the use of telephone and face-to-face encounters. MCM will provide coordination and referrals; contact clients at least quarterly; update care plans; and maintain fulltime presence in the medical clinic, five days per week, for drop in needs.  
Number of clients served: 150
- MCM will assess the transportation needs of the clients and provide assistance/resources as indicated. MCM will refer eligible clients to Ryan White transportation services; and provide bus tokens, parking coupons for clinic visits.  
Number of clients assessed: 200
- MCM will assist clients with obtaining coverage health care visits, medications and pharmacy co-pays. MCM will help eligible clients initiate applications to MADAP, PAC, DSS/Medical Assistance.  
Number of clients served: 50

- MCM will provide support, as indicated/authorized, to maintain medical care for clients who become incarcerated. MCM will communicate medical needs to correctional facilities as authorized; facilitate interim care in the clinic during incarceration; facilitate return to clinic after discharge.  
     Number of incarcerated youth served: 10
- MCM and licensed social work with facilitate a successful transition from adolescent to adult care providers; finalize policies and procedures for transitioning, educate clients and assess for transition readiness; develop transition plan; assist with facilitation of clinic transition/life skills group; coordinate referrals for adult care; communicate with adult care providers to review summary of medical care and plan for transition; review Advance Directives; follow-up with clients for a six month period to ensure that transition goals have been met.  
     Number of clients provided transitioning services: 100  
     Number of transitioned youth: 15
- MCM and social worker will refer sexually active youth for on site risk reduction and prevention counseling; incorporate risk reduction education into routine case management face-to-face sessions.  
     Number of clients served: 130
- MCM and social worker will complete assessments of parents and guardians understanding of treatment regimen and encourage involvement with treatment regimen and adherence for children and young adolescents; promote collaborative treatment planning with client and family.  
     Number of clients served: 75
- Social worker will complete assessments, and provide individual counseling and support for HIV-positive adolescents and young adults to promote successful treatment adherence. Social worker will incorporate education, adherence techniques, and clinical therapeutic strategies into sessions.  
     Number of clients served: 100
- Treatment adherence supplies, education materials and incentives will be provided to promote successful adherence to medications and appointments. These include: pill boxes, pill crushers, travel alarm clocks, dayplanner calendars, educational and workshop materials, and cell phones and minutes for clients who achieve milestones in treatment adherence.  
     Number of clients served: 50

*Evidence base / effectiveness:*

Health services are provided according to the evidence-based treatment guidelines published on line by the United States Department of Health and Human Services ([aidsinfo.nih.gov](http://aidsinfo.nih.gov)). Specific guidelines include:

- The Use of Antiretroviral Agents in Pediatric HIV infection (Dr. Hutton is a member of this national guidelines committee)
- The Use of Antiretroviral Agents in HIV-1 infected Adults and Adolescent

- Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States - July 8, 2008
- Prevention & Treatment of Opportunistic Infections in HIV Infected Adults and Adolescents

Use of these treatment guidelines within the framework of an intensive primary care (IPC) model has resulted in a remarkable track record for our patients. Despite the social and behavioral risks of our IPC client population, we have achieved impressive health outcomes, including

- o 80% survival over a twenty year period
- o 88% of clients have CD4 count greater than 200
- o 66% of clients have undetectable viral load

JHU Pediatrics case management numbers continue to increase each year. Our increasing numbers and consistently exceeded performance measures indicate (a) there are an increasing number of uninsured and underinsured HIV positive children, youth, adolescents and young adults in our community, (b) JHU Pediatrics successfully links with outreach to enroll new clients into case management, (c) JHU Pediatrics does not turn away clients even when we exceed our projections, and (d) JHU Pediatrics successfully links case management clients with HIV primary care on site. The success of our case management program is due to the strong ability of our two case managers to engage and maintain clients in ongoing, comprehensive HIV care. The case managers build a strong rapport with all of the clients and involved family members; they work diligently with our clinic youth to assess their needs and retain them in care. Our two case managers have both been in their same positions for over seven years. Their commitment to their job, despite the high rate of staff burn-out associated with this field of work, has been crucial in maintaining so many of our youth in care. The youth with perinatally acquired HIV have grown to trust and depend on our case managers over the years, and our new HIV behaviorally acquired youth also quickly begin to count on our case managers for care coordination and case management as they enter HIV care in the clinic.

*Timeline for implementation of new or expansion dollars:*

The Johns Hopkins IPC Clinic will utilize funds as soon as they become available. The Pediatric & Adolescent HIV/AIDS Medical Case Management Program is an established program and requires no additional time to utilize grant funding.

**Non-medical Case Management**

*Proposed activities / interventions, implementation, clients served, timeline:*

The goal of non-medical case management services in the IPC Clinic is to provide peer support and advocacy to our increasing number of HIV positive youth, adolescents and young adults, by providing advice and assistance with obtaining needed community, social support, financial, insurance and other identified resources. These important

services provided by our Youth Advocate assure that our clients have access to special HIV resources. The Youth Advocate in our clinic has a broad knowledge of available HIV resources, as well as in-depth experience with navigating the complicated Department of Social Services. In our experience, adolescent patients often lack the skills to advocate for themselves and do not follow up on referrals to obtain needed services. Youth Advocate involvement with assisting clients to apply for needed benefits is crucial, as many adolescents and young adults become easily overwhelmed by the complexities associated with various agencies. The Youth Advocate is able to role model effective advocacy skills and intercedes on the client's behalf when necessary.

The IPC Clinic Youth Advocate is also responsible for providing leadership for the Ryan White Part D Youth Initiative Consumer Advisory Board (VOY or Voices of Youth). In the CAB forum our Youth Advocate is able to provide information, obtain feedback from the adolescent/young adult consumers and engage HIV positive youth in the planning of care services. Our Youth Advocate is also certified to provide HIV counseling and testing; she provides this service, and risk reduction education to adolescents and young adults in the clinic setting.

Implementation date for all interventions will begin 7/1/2009 (Duration period 7/1/2009 – 6/30/2010)

- The Youth Advocate will complete an intake session with clients referred from IPC staff to identify their needs, their goals and their past history with obtaining services and advocating for themselves. The Advocate and the client will decide what referrals are needed and productively work together to obtain needed services, or Advocate provides information necessary to initiate linkages for services.  
Number of clients served: 80
- The Youth Advocate will accompany clients to agencies, in particular, the Department of Social Services to assure the application of needed services such as Medical Assistance, food stamps, and temporary cash assistance.  
Number of clients accompanied to DSS: 20  
Number of clients accompanied to other community resource agencies: 15
- The Youth Advocate will develop collaborative relationships with various agencies who provide services to HIV infected and affected clients as well as other community resources.  
Number of agency relationships developed: 10
- The Youth Advocate will provide peer support and education to newly identified HIV positive youth, adolescents and young adults.  
Number of newly identified clients served: 10
- Provide leadership and chair the Youth Consumer Advisory Board; coordinate quarterly meetings; engage youth in planning and leadership functions within the CAB.  
Number of CAB meetings held: 4  
Number of clients served: 12

- The Youth Advocate will inform youth, adolescents and young adult clients of available peer trainings such as consumer self-care, peer advocacy/leadership, and positive self worth.

Number of clients informed of trainings:	80
Number of clients who attended trainings:	10
- Total of number infected clients and affected who will receive psychosocial support services will be 300

*Evidence Base and Effectiveness:*

Johns Hopkins Pediatric HIV/AIDS Youth Advocate Program has been very successful with linking our adolescents and young adults to needed services. We have noticed that our clinic adolescents and young adults who receive aid from the Youth Advocate regarding the application for Department of Social Service benefits, are more likely to complete the application fully, receive an approval, and receive benefits (such as food stamps, temporary cash assistance and medical assistance) more quickly than our youth who apply for services on their own. Our clinic patients often comment on the benefits of having an advocate to assist them with making them aware of available resources, as well as helping (and accompanying) them to apply for eligible services.

The IPC Clinic Youth Advocate has also been very successful in assisting our teen and young adult clients, who are now parents, obtain Early Head Start and Head Start programs for their affected children. Many of the children of our teen parents now attend Martin Luther King Jr Early Head Start or Johnson Square Head Start; both of these programs are considered to be special resources for HIV infected and affected clients. Programs, such as these, are beneficial to the entire family as they provide education and structure to the child, support for the parents, and needed daycare so that infected parents are able to attend medical appointments.

Youth Advocate involvement with providing guidance and self-advocacy training has a positive impact on our adolescents and young adults, as they prepare to transition to adulthood, by providing them with early self advocacy experience.

*Timeline for implementation of new or expansion dollars:*

The Johns Hopkins IPC Clinic will utilize funds as soon as they become available. The Pediatric & Adolescent HIV/AIDS Non- Medical Case Management (Youth/Client Advocate Program) is an established program and requires no additional time to utilize grant funding.

**Outreach**

*Proposed activities / interventions, implementation, clients served, timeline:*

The goal of the Johns Hopkins Pediatric HIV/AIDS Outreach program is to provide outreach, both in the general clinic setting and in the community, in order to link and

retain newly diagnosed HIV positive youth (up to 24 years of age) into comprehensive, culturally sensitive care at the IPC Clinic; and to link identified positive clients over the age of 24 into care at adult HIV sites. Our outreach worker is a member of our interdisciplinary team; she works closely with IPC staff to re-engage HIV positive youth, who have fallen out of care, back into medical care. She also conducts social network interviewing and reaches out to at risk partners of established positive clients to encourage HIV testing and to provide risk reduction education. She provides HIV testing, counseling and referral to high risk teens identified in the Johns Hopkins Harriet Lane Adolescent Clinic. Ryan White funding is requested to continue this valuable program in order to link and retain identified children, youth, adolescents and young adults into care at the IPC Clinic, which is tailored to meet the unique needs of this high risk, vulnerable population.

Implementation date for all interventions will begin 7/1/2009 (Duration period 7/1/2009 – 6/30/2010)

- The outreach worker will provide outreach in the community to successfully link HIV positive youth and young adults into care.

Number of clients who received outreach services:	500
Number of clients identified and enrolled into care:	15
- The outreach worker will provide outreach to established clinic patients, who have missed appointments, in order to facilitate continued engagement in HIV care.

Number of clients served:	25
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- The outreach worker will coordinate and collaborate with Baltimore City Health Department to promote HIV positive youth referrals to the IPC Clinic.

Number of clients referred:	5
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- The outreach worker will investigate social and sexual network contacts of patients with HIV/STIs and track contacts to provide partner notification.

Number of clients served:	10
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- The outreach worker will provide risk reduction counseling / prevention for positives during routine clinic appointments.

Number of clients served:	130
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- Funding will be used to support the purchase of educational material and condoms for distribution at outreach events; to purchase HIV rapid test kits and control reagents (OraQuick) for outreach use to test youth in the Adolescent Clinic and engage them immediately into HIV primary care, if positive.

Number of clients served:	300
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*Evidence based / effectiveness:*

Health and Outreach services are provided according to the evidence-based treatment guidelines published on line by the United States Department of Health and Human Services ([aidsinfo.nih.gov](http://aidsinfo.nih.gov)). Specific guidelines include:

- Revised recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in the Health Care Setting (September 22, 2006)

- The Use of Antiretroviral Agents in Pediatric HIV infection (Dr. Hutton is a member of this national guidelines committee)
- The Use of Antiretroviral Agents in HIV-1 infected Adults and Adolescents
- Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States - July 8, 2008
- Prevention & Treatment of Opportunistic Infections in HIV Infected Adults and Adolescents

Use of these treatment guidelines within the framework of an intensive primary care (IPC) model has resulted in a remarkable track record for our patients. Despite the social and behavioral risks of our IPC client population, we have achieved impressive health outcomes, including

- o 80% survival over a twenty year period
- o 88% of clients have CD4 count greater than 200
- o 66% of clients have undetectable viral load

Outreach services located, on the site of both the IPC and JHH Adolescent Clinic, have been very effective with identifying high risk youth, providing education, and successfully linking youth to HIV care and resources. The outreach worker is able to utilize immediate support from all interdisciplinary members of the IPC team. During the year 2007-2008, the IPC Clinic received 15 newly identified clients for comprehensive HIV and primary care, through received referrals and outreach efforts. Outreach has also been beneficial with assisting our adolescents and young adults with disclosure techniques / support. Outreach has effectively reached out to positive adolescents, young adults and their partners and friends to encourage HIV testing. Risk Reduction education, as well as counseling and testing, provided by our Outreach worker has proven successful with linking youth to services. The IPC team also values the outreach effort to re-engage youth who may periodically drop out of care; the worker is often successful with locating the client so that client can be encouraged to resume HIV care.

*Timeline for implementation of new or expansion dollars:*

The Johns Hopkins IPC Clinic will utilize funds as soon as they become available. The Pediatric & Adolescent HIV/AIDS Outreach Program is an established program and requires no additional time to utilize grant funding.

### **Psychosocial Support**

*Proposed activities / interventions, implementation, clients served, timeline:*

The IPC clinic has provided pediatric, adolescent and family psychosocial support and counseling services on site since 1988. Our current program is directed by a certified child life specialist who performs a variety of functions to include: individual psychological preparation for medical procedures, HIV disclosure and medication

changes to promote coping skills and adherence. She coordinates the “Big Buddy Program”, group sessions, recreational outings, therapeutic camping and weekend retreats to reduce social isolation and stigma. The Child Life Specialist is also crucial in providing support around end-of-life issues, advance directives and bereavement support for our clients and family members.

Ryan White Part D and State General funding is requested to continue and expand available *Psychosocial Support Services* in order to include a new, IPC Clinic initiative directed at our aging clinic population. This initiative will aim to promote treatment adherence through the use of individual sessions and informational group workshops in order for our adolescents and young adults to gain knowledge and life skills needed to facilitate a successful transition to independence and adult medical care. For many patients, medical needs have superseded social, educational, and developmental goals for much of childhood and adolescence. In addition, many perinatally infected children are orphaned at an early age and may lack consistent adult role models. As they reach late adolescence and young adulthood, they are expected by family members and society to take on adult responsibilities relating to housing, social services, financial management, and employment, but lack the skills necessary to succeed. This initiative would support two life skills coaches to provide individual coaching and group workshops for HIV infected youth to gain skills for independent living, such as budgeting, shopping, cooking, and resume writing; and to gain knowledge and skills needed for the successful transition of HIV medical care to adult providers and clinics. Funding would also support a full time social worker dedicated to provide family-centered psychosocial assessment and counseling for HIV-exposed and infected infants, children, youth, adolescents and young adults.

Implementation date for all interventions will begin 7/1/2009 (Duration period 7/1/2009 – 6/30/2010)

- The Social Worker will provide assessment of client’s needs; provide individual /family centered counseling; develop an individualized care plan; collaborate with client’s primary provider and nurse case manager; attend weekly IPC team case conference meetings.  
Number of clients served: 100
- The Child Life Specialist will provide individual and group activities to promote coping with medical care, procedures, medication adherence, and challenges associated with treatment adherence; develop care plan for client/group, collaborate with IPC team members; attend weekly IPC team case conference meetings.  
Number of clients served: 90  
Number of group activities/sessions: 12
- The Life Skills Coach will provide individual coaching and workshops for HIV positive youth to gain independent skills in medical self-management, such as tracking prescription refills, renewing health benefits, tracking medical appointments and maintaining a calendar, and personal self management such as budgeting, cooking, shopping resume writing; develop care plans/group

curriculum; collaborate with IPC team members; attend weekly IPC team case conference meetings.

Number of clients served: 50

Number of group activities/sessions: 12

- The Life Skills Coach will provide individual coaching and group workshops for youth to gain knowledge and skills for transition to adult medical care sites, such as knowing your medical history, insurance options, choosing an adult provider and negotiating new systems; develop care plans/workshop curriculum; collaborate with IPC team members; attend weekly IPC team case conference meetings.

Number of clients served: 50

Number of workshops: 12

- Funding will be used to support client incentives to attend the life skills and transition workshops. Incentives will include cookbooks, GED books/fee for test, SAT prep books, gift cards and basic household supplies for clients who achieve milestones in the transitions program.

Number of clients served: 50

- Total of number infected clients and affected family members who will receive psychosocial support services will be 300

*Evidence based / effectiveness:*

Health and psychosocial services are provided according to the evidence-based treatment guidelines published on line by the United States Department of Health and Human Services ([aidsinfo.nih.gov](http://aidsinfo.nih.gov)). Specific guidelines include:

- The Use of Antiretroviral Agents in Pediatric HIV infection (July 29, 2008) (Dr. Hutton is a member of this national guidelines committee)
- The Use of Antiretroviral Agents in HIV-1 infected Adults and Adolescents
- Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States - July 8, 2008

Use of these treatment guidelines within the framework of an intensive primary care (IPC) model has resulted in a remarkable track record for our patients. Despite the social and behavioral risks of our IPC client population, we have achieved impressive health outcomes, including

- o 80% survival over a twenty year period
- o 88% of clients have CD4 count greater than 200
- o 66% of clients have undetectable viral load

The incorporation of psychosocial services, support and programs to the IPC Clinic has positively impacted the client / families' ability to remain engaged and adherent in HIV care. These programs have noticeably improved the capability of children, youth, adolescents and young adults to cope with medical visits, prescribed treatment, and

living well with HIV. Psychosocial support and programs reduce social isolation and promote peer support. The transition and life skills program has assisted our adolescents and young adults as they prepare to transition; we hope to see this progress advance even more towards independence as we intensify our transitions program to include group and individual life skills coaching and resources. The psychosocial staff members on the IPC team are highly valued staff members by both the medical providers and our IPC clients and families.

*Timeline for implementation of new or expansion dollars:*

The Johns Hopkins IPC Clinic will utilize funds as soon as they become available. The Pediatric & Adolescent HIV/AIDS Psychosocial Program is an established program and requires no additional time to utilize grant funding.

## **5. STAFFING PLAN**

Please see Budget Justification in Section 7 for full details of Part Specific Funding  
Please see the Organizational Chart, Resumes, and Licenses in the Appendix

### **Ambulatory Outpatient Medical Care Services**

a) The following staff are proposed to carry out this project:

HIV Specialist Physician (30 %)

Dr. Nancy Hutton is the program director for the Pediatric & Adolescent HIV/AIDS Program. Dr. Hutton is a licensed medical physician in the state of Maryland. She will devote 30% effort providing direct medical care for HIV exposed/ infected underinsured infants, children, and youth. She is an internationally known expert pediatric and palliative care medical provider.

Adolescent Medicine Physician (10%)

Dr. Stephanie Crewe will devote 10 % effort providing ambulatory outpatient medical services for HIV-infected youth, adolescents and young adults who are underinsured. Dr. Crewe is a licensed medical physician in the state of Maryland.

Research Coordinator (5%)

Ms. Joan Bess will devote 5 % effort to provide education about clinical research and voluntary access to active research protocols for HIV-exposed and infected infants, children, and youth. Ms. Bess has a bachelor's degree in health science; she is CCRP certified (Certified Clinical Research Professional)

*b) )Initial and on-going training available:*

The primary care providers assigned under this proposal are already experienced HIV care providers. Providers are encouraged to attend trainings and conferences to remain current regarding HIV management, use of antiretroviral medications, use of advanced laboratory monitoring, adherence techniques, special adolescent populations, cultural competency, or other topics of interest to the primary care team. Annual courses are offered locally by the AIDS Education and Training Center (AETC). Ongoing training also occurs at weekly two hour team meetings where both clinical and educational information is discussed. Guest speakers routinely are invited to this

meeting, by our Program Director, to provide ongoing training. Recently our clinic staff received an onsite training regarding best care practices for transgender youth / clients.

Ms. Bess reports to the IPC Clinical Director, Dr. Hutton, for programmatic support and to the Johns Hopkins IMPAACT Principal Investigator for IMPAACT support and supervision. Ms. Bess attends weekly team IPC meeting for ongoing support and education; she is also encouraged to take advantage of continuing education opportunities.

Initial training, if needed, would involve an orientation to the Ryan White Care Act, Standards of Care, and available services; HIV/AIDS education; cultural competency; as well as an orientation to Johns Hopkins Hospital policies and clinic / program specific policies and procedures.

### **Mental Health Services**

#### a) Proposed staffing:

##### HIV Psychiatrist (15%)

Dr. Lawrence Wissow will devote 15 % effort to provide direct psychiatric services (including in depth adherence assessments) for HIV-infected children, youth, adolescents and young adults who are underinsured. Dr. Wissow is a licensed physician in the State of Maryland; board certified in both general and child psychiatry, with expertise in working with HIV-affected children and families.

##### HIV Youth Social Worker (60%)

Ms. Nancy Sybert, MSW, LGSW will devote 60 % effort to provide psychosocial assessment and mental health counseling for underinsured HIV-infected youth under the clinical supervision of the HIV psychiatrist. Ms. Sybert is a licensed clinical social worker in the State of Maryland; she has extensive experience working with adolescents with HIV.

##### Complimentary Alternative Medicine Specialist Physician (10%)

Dr. Erica Sibinga will devote 10 % effort to provide complementary medicine services including mindfulness-based stress reduction (MBSR) for HIV-infected youth. Dr. Sibinga is a licensed physician in the State of Maryland.

#### b) *Initial and on-going training available:*

The providers assigned under this proposal are also experienced HIV care service providers. Dr. Wissow and Dr. Sibinga are encouraged to attend trainings and conferences to remain current regarding HIV as it relates to psychiatry and complimentary medicine. Dr. Wissow and Dr. Sibinga are supported by the IPC Director for supervision and program issues. Ms. Sybert reports to both the IPC Clinical Director for program supervision and to the Johns Hopkins Senior Adolescent Social Worker for professional supervision. Ms. Sybert also receives clinical supervision from Dr. Wissow. Ms. Sybert must attend 42 hours of continuing education units, during a two year period, to maintain Maryland licensure. Dr. Wissow and Ms. Sybert also attend weekly IPC team meetings for ongoing support and education.

Initial training, if needed, would involve an orientation to the Ryan White Care Act, Standards of Care, and available services; HIV/AIDS education; cultural competency; as well as an orientation to Johns Hopkins Hospital policies and clinic / program specific policies and procedures.

### **Medical Case Management including Treatment Adherence Services**

a ) Proposed staffing:

#### HIV Medical Case Manager (40%)

Ms. Carolyn Kiefner, RN, BSN will devote 40 % effort to provide medical case management services for HIV-exposed and infected infants, children and youth who are underinsured. Ms. Kiefner is a licensed Nurse in the State of Maryland; she has forty years of nursing experience and extensive pediatric and HIV experience.

#### HIV Medical Case Manager (40 %)

Ms. Jamie Rogers, RN, BSN will devote 40 % effort to provide medical case management services for HIV-infected youth, adolescents and young adults who are underinsured. Ms. Rogers is a licensed Nurse in the State of Maryland with extensive pediatric, adolescent and HIV experience.

#### HIV Youth Social Worker (80%)

This position to be announced will provide adolescent specific psychosocial assessment, counseling, and support for HIV-positive youth to promote successful treatment adherence. This new position, which is currently being recruited, will be held by a MSW who is a licensed clinical social worker in the State of Maryland.

b ) *Initial and on-going training available:*

Ms. Kiefner and Ms. Rogers both have extensive nursing, HIV and case manager experience. They attend weekly IPC meetings for ongoing education and support; they are also encouraged to attend available HIV related conferences and trainings. Both report to The IPC Clinic Director for programmatic supervision and to the Johns Hopkins Hospital Director of Pediatric Nursing for professional supervision.

The new social worker will report to the IPC Clinic Director, Dr. Hutton, as well as to The Johns Hopkins Adolescent Clinic Senior Social Worker for clinical supervision. He or she will receive initial training to include an orientation to the Ryan White Care Act, Standards of Care; HIV/AIDS education; cultural competency; as well as an orientation to Johns Hopkins Hospital policies and clinic / program specific policies and procedures.

### **Non-Medical Case Management Services**

a ) Proposed staffing:

#### HIV Youth Advocate (100 %)

Ms. Angela Williams will devote 100 % effort to provide individual non-medical case management services for HIV-positive youth to promote adherence to care and to help them negotiate complex tasks, such as DSS enrollment, Social Security, housing agreements, as independent young adults. She will also coordinate the Youth CAB. Ms. Williams has five years Youth Advocate experience; she has extensive knowledge of HIV resources.

b ) Initial and on-going training:

Ms. Williams has five years Youth Advocate experience; she has extensive knowledge of special HIV resources. She has completed HIV Level I and she has her CTR (Counseling, Testing and Referral) certification. She has attended numerous trainings and conferences related to HIV Advocacy, leadership, positive self management, women and HIV and cultural competency. She is supervised directly by Nancy Sybert who is a licensed graduate social worker with 5 years experience in providing direct HIV client services. Ms. Williams and Ms. Sybert meet for weekly supervision and more often when needed.

**Outreach Services**

a ) Proposed staffing:

HIV Youth Outreach Worker (100 %)

Ms. Melody Lynch will devote 100 % to provide outreach to individuals and agencies to engage and maintain HIV-positive youth in HIV primary care; to provide rapid HIV testing for the Johns Hopkins Adolescent Clinic, and risk reduction counseling for HIV – positive youth and their partners. Ms. Lynch has a Bachelors of Science and past experience working with adolescents in the Baltimore community.

b ) Initial and on-going training:

Ms. Lynch has attended several HIV trainings sponsored by the Institute of Human Virology since her employment began in August 2008. She also completed the CDC Disease Intervention Specialist training; she completed HIV Level I and obtained her CTR certification. Ms. Lynch received initial IPC training related to the Ryan White Care Acts, Standards of Care, and IPC Clinical program; she also completed all required JHU Orientation. She attends weekly team IPC meetings for ongoing education and support. She is supervised directly by Nancy Sybert, LGSW; she also is supervised by the IPC Clinic Director for programmatic issues.

**Psychosocial Support Services**

a ) Proposed staffing :

HIV Medical Social Worker (100 %)

Ms. Stephanie Lee, MSW., LGSW will devote 100 % effort to provide family-centered psychosocial assessment and counseling for HIV-exposed and infected infants, children, and youth. Ms. Lee is a licensed clinical social worker in the State of Maryland; she has extensive experience working with adolescents with HIV.

HIV Child Life Specialist (35 %)

Ms. Cora Welsh, B.S., CCLS will devote 35% effort to provide individual activities and group sessions to promote coping with medical care, procedures and treatment adherence. Ms. Welsh has many years experience working with children and adolescents with HIV; she also has palliative care knowledge and experience.

Life Skills Coach (75 %)

Ms. Adowa Weaver will devote 75% effort to provide individual coaching and group workshops for HIV-infected youth to gain skills needed for independent living and skills and self management skills to make a successful transition to living independently.

Life Skills Coach (55 %)

Ms. Jennifer Chang will devote 55% effort to provide individual coaching and group workshops for HIV-infected youth to gain knowledge and skills needed for a successful transition of medical care to adult clinics and providers.

b ) Initial and ongoing training:

All of the proposed staff for this project has a great deal of knowledge of experience related to HIV and adolescents. All staff attends weekly IPC team meetings for ongoing education and support. Ms. Lee, LGSW, is required to obtain 42 continuing education units during a two year period in order to maintain her Maryland Social Work license. Ms. Welsh, CCLS, is required to obtain 60 professional development hours of training over the course of 5 years in order to renew Child Life Specialist certification. Ms. Welsh is also currently attending classes to obtain her Masters in Spiritual Counseling. Ms. Lee and Ms. Welsh will report to the IPC Clinic Director, Dr. Hutton for programmatic supervision. Ms. Lee will report and meet regularly with The Johns Hopkins Adolescent Clinic Senior Social Worker for clinical supervision, and Ms. Welsh will receive professional supervision from the Johns Hopkins Hospital Director of Child Life.

Ms. Weaver has extensive experience with, HIV youth/adolescent programming, administrative / business functions as well as entrepreneur experience as a Pampered Chef Sales Consultant and Manager; these important skills and knowledge will be incorporated into the life skills coaching and work shop program. Ms.Chang also has a great deal of experience related to HIV care, medication / treatment regimens, insurance programs and navigating complicated systems, Ms. Weaver and Ms. Chang will report directly to The IPC Clinic Director, Dr. Hutton; they will also both receive consistent support and supervision from Ms.Lee, Ms. Sybert and Ms. Welsh to monitor progress and achievement of transition program goals.

## 6. EVALUATION/QUALITY IMPROVEMENT

- ***a ) Continuous Quality Improvement (CQI) process***

- (i) *Staff composition and participation in CQI*

Clinical Quality Management (CQM) is an integral process to assure we meet or exceed published standards of care in order to achieve optimal health outcomes for our clients and families. Dr. Nancy Hutton is Director of the IPC Clinic and is responsible for overseeing the CQM Program. The interdisciplinary IPC Team is responsible for identifying quality goals, monitoring quality indicators, and assessing progress in meeting quality goals.

- (ii) *Formalized mechanisms to implement CQI*

1. Clinic director oversees CQM program. (Hutton)
2. CAREWare data manager generates reports. (Weaver)
3. Care coordinators review laboratory results daily with discussion as needed with the primary medical providers and documentation in medical records. (Kiefner, Rogers)
4. Medical providers and care coordinators review medical records prior to visits to ascertain which patients are due for tuberculosis testing, immunization, or laboratory tests. (Hutton, Joyner, Knott-Grasso, Kiefner, Rogers)

5. IPC Clinic interdisciplinary team reviews progress in meeting CQM goals at weekly team meetings to monitor the efficacy of services provided, identify which patients/families require additional services, and assure that standards of care are being met.
6. Social workers and care coordinators assess and review Ryan White eligibility. (Sybert, Lee, Rogers, Kiefner)

*(iii) Performance indicators*

The following are established priorities of the IPC Program. Goals 1-2 are client specific outcomes. Goals 3-4 are clinical practice outcomes. Goal 5 is an administrative outcome.

1. More than 50% of IPC clients will maintain non-detectable HIV viral load
2. More than 50% of IPC clients will maintain CD4 > 200
3. 80% of IPC clients will be up to date with recommended vaccines
4. 90% of IPC clients will have documentation that Ryan White eligibility is assessed at least annually.
5. IPC Clinic will submit timely and accurate reports to funding agencies as required in conditions of award.

Methods for monitoring performance indicators are detailed in the Agency Clinical Quality Management Plan (Appendix)

*(iv) Use of CQI findings to change program*

Annual review of CQM Program activities and success in achieving quality goals is conducted in December each year. Goals are defined for the coming year and CQM practices are revised as necessary to achieve goals. IPC Clinic director is responsible for scheduling and conducting this annual review with the full IPC Clinic Team. Recent examples of CQM findings and changes include (1) episodes of virologic failure in adolescent patients leading to more intensive and structured adherence program, and (2) completed hepatitis A vaccine administration in clinic population therefore changing CQM focus for 2009 to hepatitis B immunization.

**• b ) Project Monitoring and Evaluation:**

The six requested service areas (Outpatient/ambulatory Health, Mental Health Services, Medical Case Management, Non-Medical Case Management / Youth Advocate, Outreach, and Psychosocial Support) will all be monitored on a regular basis. Proposed performance measures and number of clients served will be reviewed. Progress, areas of strengths and areas to improve will be discussed during our IPC interdisciplinary team monthly meeting devoted specifically for program monitoring and review of performance measures and service category goals. Progress made towards goals and proposed performance associated with each service category will be reviewed for measures of success. Ongoing monitoring of service category progress will also occur with staff member's individual supervisors as well as the IPC Program Director, Dr. Nancy Hutton.

**7. BUDGET**