

# Identifying HIV-Positive Youth and Transitioning Them into the Health Care System

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## Introduction

When CHRRPY was initially funded, the Chicago Department of Public Health (CDPH) estimated that 3.4 percent of 21,000 projected cases of HIV infection would be seen in youth 10 to 19 years old. However, HIV counseling and testing efforts within Chicago had identified fewer than 15 HIV-positive youth annually. In the CDPH testing sites, of 3,679 youth age 12-19 presenting for testing, only four were HIV positive. It is unclear how many returned for post-test counseling and results, although statistics from CDPH showed that fewer than 50 percent of individuals who got tested for HIV actually returned to get their results. It was also unclear whether these youth have accessed other health services. The mission of CHRRPY was to identify and care for the 700 Chicago youth who are falling through the structural and legal gaps in the health care system.

A needs assessment of the system before the project was initiated indicated three major barriers to service: (1) many testing sites are not in youth-friendly environments and personnel are often perceived as insensitive by youth, (2) there is no support system that would allow youth to overcome their fear and anxiety when testing for HIV, (3) communication between counselors and youth being tested is weak. Providers are perceived as judgmental by youth and providers' knowledge and understanding of youth is limited.

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## Introduction

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## **Model of Care and Services**

CHRRPY was created to address the major barriers youth face when accessing services. CHRRPY used an outreach team that included an outreach worker/ phlebotomist (called a case finder), who was trained to be sensitive to adolescent issues, and a youth peer educator. They traveled to various agencies that served high-risk youth throughout the city of Chicago and provided on-site HIV education, counseling and testing, and referral services. These outreach teams were developed to link HIV-positive adolescents to primary care services. To conduct its outreach services, the CHRRPY project linked with community agencies including: a social support agency serving gay youth, an HIV prevention agency, an alternative educational program for students who had dropped out of school, an alternative high school, several agencies providing services to homeless youth, an agency with programs for gang members and substance abusing youth, an agency that houses youth detainees, and the state agency responsible for guardianship of wards of the state.

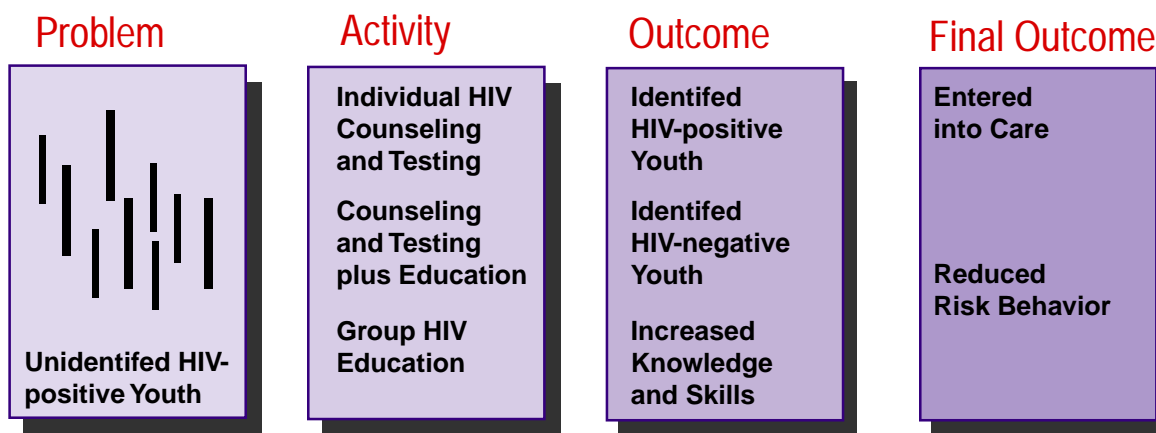
The program has three goals: (1) increase the number of youth receiving counseling and testing for HIV, especially those who were in high-risk situations, and thereby increase the number of HIV-positive youth aware of their serostatus, (2) use the HIV testing period as an integral component of an HIV intervention designed to reduce youth's risky behaviors, and (3) increase the number of HIV-positive youth entered into comprehensive medical and mental health services. These goals are pursued by developing a system of HIV case identification through use of community and school adolescent service centers, and with the participation of adolescent peer educators identified to work with targeted youth.

The educational sessions are conducted in groups and focused on HIV and sexually transmitted disease (STD) transmission and preventive skills, e.g., using condoms (and other safer sex practices) and cleaning drug paraphernalia. After each educational session, youth are offered individual HIV counseling and testing services using blood-draw procedures (switching to Orasure testing in 1999). While not all agencies are able to accommodate the program's educational sessions, all agencies utilize the program's HIV counseling and testing services. As part of the counseling and testing procedures, youth are assessed as to their personal risk behaviors, coping abilities and support systems. In addition, each counseling and testing session, including post-test counseling, are used as an opportunity for personalized HIV risk reduction education. Once an HIV infected youth is identified, they are assisted in transitioning to an adolescent-specific comprehensive health care clinic for early intervention and treatment. The project provides developmentally appropriate comprehensive HIV medical care, mental health care, nursing and case management.

## **Lessons Learned**

### **Lesson #1: Outreach workers are difficult to hire and train.**

CHRRPY wanted each outreach worker to represent several at risk populations of youth, have a college degree and have good writing abilities with knowledge of computers—especially with word processing. None of the final panel of applicants selected for these positions possessed college degrees. The three applicants selected had extensive experience in performing outreach and HIV education, especially with youth. However, they lacked formal knowledge of adolescent development, had no



### CHRRPY Model of Outreach and Transitioning Youth in to Health Care Services

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certification in HIV counseling and testing, and two of the three applicants had no experience in phlebotomy. Formal phlebotomy certification required a six-month course sponsored by one of the community colleges. With this limitation, the director of the laboratory at CHRRPY organized his phlebotomy team to provide an intensive training program for the three outreach workers. The outreach workers also required orientation in body substance and infectious control, and Red Cross HIV counseling and testing certification. Finally, the outreach workers had to learn group facilitation and presentation skills for working with youth.

Presently, with the introduction of Orasure, the need for phlebotomy training is obsolete. However, finding adult providers who are youth sensitive, who can engage and encourage youth, and who can respect boundaries, especially in a work environment, are difficult to recruit and employ.

#### **Lesson #2: Review agreements annually.**

Turnover at the partnering agencies required renegotiation and re-establishment of letters of agreement with CHRRPY. One partnering agency did not replace a person critical to the function of the partnership, did not send out its workers to conduct street outreach as originally proposed in the letter of agreement, and did not respond to requests to meet to discuss resolution of these problems. Another agency lost its executive director, merged with another agency for survival and underwent a needs reassessment. This agency then became partners with another agency that provided services similar to those being offered by CHRRPY. Finally, a third agency was structured such that it was difficult to gather youth into groups for educational sessions. This agency moved twice over the period of the letter of agreement.

CHRRPY's contract with HRSA stipulates providing HIV counseling and testing to youth nineteen years and younger, however, most of the agencies linked with CHRRPY serve youth clients extending to age 24. These agencies were upset when youth over the age of 19 were denied the counseling and testing. The program was consequently modified to serve youth up to the age of 24. Another problem was that agencies generally opened for services around 4 p.m. and closed to the outside between 7:30 and 9 p.m. This left little time for the counseling, testing and educational programs of CHRRPY and required precise scheduling.

### **Lesson #3: To identify and help HIV-positive youth, gear the program for youth, not adults.**

Focus groups of youth seeking services within the adolescent and young adult clinics reveal that youth who had previously consented to HIV testing in existing clinics for adults are unhappy with these services and identified the following issues:

- Providers are not youth sensitive and youth felt that they could not openly discuss issues that were key to them in engaging in risky behaviors. Further, youth felt that adult providers were critical of their lifestyles, ways of dressing and of their sexuality.
- Undocumented youth felt that existing sites did not allay their fears of being reported to INS for deportation despite seeking only HIV testing.
- Many sites are across gang territories and cannot understand youth's difficulty in returning for post-test counseling and test results.
- Many sites are open only during school hours making post-test counseling difficult to attend.

#### *Case finding*

The work of case finding and follow up is labor-intensive and costly. A constant process of engagement and stabilization of youth throughout all project services is key to transitioning youth into care. Youth identified in the community may require intensive manpower, intensive involvement by case finding and clinic staff for tracking these youth and for complying with their first clinic appointment. Some youth may require a number of phone calls, and direct face-to-face contacts in the community or at their homes before reaching their first clinic visit.

Youth who developed relationships with the CHRRPY outreach workers were more likely to enter into care than youth who were unknown by the outreach workers. Case finders report that developing an ongoing presence at assigned community agencies and engaging youth in discussions about topics beyond HIV 101 allow for an easier and more successful process of transitioning identified HIV-infected youth into care. Youth who are not previous clients of the community agency and who are new to all services are more likely to be untrusting of medical services when diagnosed as HIV infected. As such, a therapeutic relationship must also be tendered at the assigned agency by the case finder and the youth population.

#### *Forming partnerships*

Partnerships with community agencies with the goal of developing a citywide infrastructure to identify HIV-infected youth has been highly successful in getting youth into care. Youth agencies providing services to subcultures of youth (homeless, gay youth, school drop outs/pushed out; Latino youth, African-American youth, etc.) partnered with CHRRPY and sought CHRRPY services for their clients for HIV education, counseling and testing, referrals for adolescent specific primary care including STD screening and treatment, and mental health services.

### *Staffing with youth*

The availability of youth peer health educators is a continual problem. However, since many youth clients are more receptive to prevention information when delivered by peers, having a youth organization and youth cab available as a pool of peer health educators is critical for continued project's delivery of services and continued development. Two peer educators were relieved of their jobs for failing to continue to perform according to their job descriptions. Other peer health educators were in school. With their school commitments and struggles with increased responsibilities in their lives, forming goals and future plans for themselves, not many youth peer health educators are available for educational sessions at the agencies. Also, some of the peer educators are HIV positive and dealing with life issues themselves. These life issues for both HIV-positive and HIV-negative youth might include being homeless, dealing with substances, engaging in unprotected sex during vulnerable moments and identifying with the very youth they are educating.

Developing a youth peer health organization is critical for ongoing project services and project development. The project has helped to develop Chicagoland Youth Against AIDS, an organization of youth peer health educators reflecting youth from varied subcultures and organizations. This peer-led organization has provided a continued source of peer health educators, continues the outreach work of informing community agencies, schools and churches about HIV prevention services at CHRRPY, serves as CHRRPY's community advisory board, serves as a source of youth buddies for other infected clients, and helps with program development.

A pool of peer health educators is critical for continued... delivery of services...

### **Lesson #4: Youth's perception of treatment differs from adults'.**

Requirements of daily living take precedence over medication startup or medication adherence. Youth who live in unstable housing situations report that they could not consider starting medication. In fact, chart reviews reveal the worst treatment adherence among youth with unstable housing. Youth who have housing, food, clothing and mental health services are in better positions to consider medications long term.

Youth prefer no medications and worsening biological markers over medications with side effects and improving biologic markers. Even among the youth who are most active as advocates for themselves and who serve as role models for other youth, side effects of medications are likely to influence non-adherence and ceasing treatment, even when medications are shown to improve CD4 and viral load levels.

## **CHRRPY ProjectChronology**

### **October 1996**

- Hire project manager and evaluator.
- Initiate evaluation protocol and instrument development and education protocol development.

- Notify agencies of award (six agencies).
- One agency lost due to misunderstanding of project budget.
- Create agency linkages and project plans (five agencies).
- Orient agency staff concerning CHRRPY (three agencies).

### **November 1996**

- Begin interviewing for outreach worker/phlebotomists positions.
- Establish peer training protocol and quality assurance plan.
- Initiate agreement with laboratory for HIV antibody tests.

### **December 1996**

- Peer educator recruitment initiated.
- Initiate the process of reaching formal agreements with agencies.

### **January 1997**

- Hire outreach workers.
- Begin outreach worker orientation and training.
- Finalize pilot evaluation protocol and quality assurance plan.
- Formal phlebotomy training developed.

### **February 1997**

- Start up project at two agencies.
- Begin data collection.
- Initiate weekly outreach worker meetings.
- Outreach workers obtain HIV Instructor Certification.

### **March 1997**

- Start up project at one agency.
- Complete first agency interviews.
- Clarify and adjust agency linkages and project plans (two agencies).
- Develop policy for adult employees who work with youth.
- Protocol developed for outreach worker to administer education and HIV counseling.
- Add testing site.

### **April 1997**

- Adjust HIV counseling and testing service protocol, extending age to 24.
- Outreach worker performance evaluations initiated.
- Sign original letter of agreement with one site.
- Start up project at one agency.

### **May 1997**

- Complete additional agency interviews.
- Assess pilot evaluation protocol/instruments and education protocol.

### **June 1997**

- Start up project at three additional agencies.
- Finalize agreements with five of seven initial agencies and one new agency, evaluation protocol and instruments and education protocol.
- Establish quality assurance plan for education session.

### **July 1997**

- Develop intake form and buddy system for HIV positive youth; system for re-contacting for follow-up and initiate first follow-up surveys; data coding/entry system.

### **September 1997**

- Finalize multisite evaluation protocol and instruments.
- Secure the services of a volunteer data entry person.
- Start data coding/entry.

### **October 1997**

- Hire new outreach worker and two peer health educators.
- Youth peer role playing sessions developed.
- Outreach workers complete training.

### **November 1997**

- Start up projects at an additional agency and site.
- Begin negotiations to provide HIV education and counseling and testing.
- Project evaluation and management team receive multisite data training.
- Develop peer education manual.
- Project evaluator enters into an official contract.

### **December 1997**

- Develop linkage agreement with an alternative high school.
- Begin preliminary analysis on data.

### **January 1998**

- Start up project at an alternative high school.
- Present preliminary findings at SPNS conference.
- Initiate new qualitative techniques into data collection efforts.

### **February 1998**

- Start up project at an additional agency.

- Start negotiations with the state and city health departments to switch to Orasure for HIV testing.

### **March 1998**

- Conduct two agency-collaborative role playing workshops for youth.
- Start up project at two agencies.

### **April 1998**

- Conduct STD/HIV in-service educational program for participating agency staff.
- Start up project at two agencies.
- Youth hired as part-time data entry person.

### **May 1998**

- Advise the city HIV Planning Council and the HIV Coordinated Care Committee on adolescent HIV issues.

### **June 1998**

- Identify case management needs for HIV-positive youth.

### **July 1998**

- Start up project at citywide sites.
- HIV-positive youth invited to participate in video to teach high school youth about HIV/AIDS.

### **September 1998**

- Develop a support group for HIV-positive youth.
- Develop an evaluation plan for the support group.

### **October 1998**

- Conduct workshops for adult providers of HIV adolescent services.
- Conduct teacher workshops for the public school system.
- Conduct workshops for adult providers of HIV adolescent services.

### **November 1998**

- Hire case manager for newly-identified HIV-positive youth.
- Formalize the primary care team approach for HIV-positive youth.

### **December 1998**

- Outreach worker resigns.
- Identify need for additional training of all case managers.
- HIV-positive youth participate as speakers at the Mayors World AIDS day.

### **January 1999**

- Initiate search for outreach worker replacement.

- Reassign outreach workers to agencies until replacements are hired.
- Discontinue services at two locations due to low turnout.

### **April 1999**

- Request supplemental resources to conduct survey of youth.
- Coalition building with partner agencies begins.

### **May 1999**

- Host conference on infrastructure building for adolescent HIV case finding among participating agencies.
- Project coordinator resigns.

### **June 1999**

- Expand hours of service at one agency at their request.
- Initiate search for project coordinator replacement.
- HIV-positive youth participate in video.

### **July 1999**

- Initiate Orasure as method of HIV testing at all but one agency.

### **August 1999**

- Develop the risk profile format for individual agency case studies.

### **September 1999**

- Hire new project coordinator.

### **October 1999**

- Begin orientation and training of new outreach worker case finder.

### **November 1999**

- Participate in health fair.
- Conduct HIV/AIDS conference.

### **December 1999**

- Terminate one outreach worker.

### **January 2000**

- Adult outreach worker and youth peer educator assigned to temporary juvenile detention center to conduct education, counseling and testing.
- Hire youth as data entry person.
- Hire of outreach worker.
- Hire nurse to transition youth into care for CHAMP initiative.

### **February 2000**

- Hire case manager to transition youth into care for CHAMP initiative.

## March 2000

- HIV-positive youth conduct workshops for public school system.
- Conduct training workshops for outreach workers and youth peer educators.

### **Further Information and Technical Assistance**

Should you wish to obtain additional information about the service delivery model developed by the Chicago HIV Risk Reduction Partnership for Youth (CHRRPY), you are welcome to contact the project director and request technical assistance:

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