

ORIGINAL ARTICLE

The University of Minnesota Youth and AIDS Projects' Adolescent Early Intervention Program

A Model to Link HIV-Seropositive Youth with Care

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The survival of human immunodeficiency virus (HIV)-positive adolescents may be abbreviated by delays in health care delivery. Methods of linking youth with services have not been well studied. With support from the Special Projects of National Significance Program, the Youth and Acquired Immunodeficiency Syndrome (AIDS) Projects' (YAP) Adolescent Early Intervention Program offers early intervention health care services to all affected youth in Minnesota, a state with mandatory reporting of HIV/AIDS cases. The conceptual framework is a novel application of traditional public health disease surveillance strategies to link HIV-positive adolescents with health care services. The target population is composed of all 13–22-year-old HIV-positive persons reported to the Minnesota Department of Health (MDH). MDH staff locate and contact HIV-positive youth, conduct structured interviews regarding health status and needs, and facilitate enrollment at YAP. Sixteen male and 20 female participants (mean age 21 years; 56% people of color; 32% gay or bisexual) reported serious health risks, including inconsistent condom use (83%), poverty (78%), high school dropout (56%), unemployment (50%), illegal conduct (50%), medical debt (42%), unstable living situations (33%), running away (33%), substance abuse (33%) and attempted suicide (28%). More than one third reported each of six HIV-related symptoms. Seventy-five percent of participants sought advocacy/case coordination; 56%, clinical trials of experimental therapies; and 50%, vocational training and access to entitlement/eligibility programs. Linking HIV-positive youth to care is a

valuable extension of the work of disease intervention specialists in states with similar reporting systems. © Society for Adolescent Medicine, 1998

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In 1991–1992, the University of Minnesota Youth and Acquired Immunodeficiency Syndrome (AIDS) Projects (YAP) and the Minnesota Department of Health (MDH) designed a program to study the health outcomes of persons diagnosed with human immunodeficiency virus (HIV) infection during adolescence and to link participants with medical and psychosocial services. This pilot program became the template for the Adolescent Early Intervention Project, a project funded by the Special Projects of National Significance (SPNS) Program at the Health Resources and Services Administration.

The goal of the demonstration project has been to prevent morbidity and premature mortality among HIV-positive adolescents. To accomplish that, a pre-established public health HIV disease surveillance system was joined with a health care program for HIV-positive adolescents. The end result has been a model collaboration to create uniform access to health care for an underserved and hard-to-reach population of youth with serious chronic illness.

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The purpose of this article was to describe the project for other agencies and localities that might adopt a similar approach. The article describes the project's setting, conceptual framework, intervention methods, and ongoing evaluation. Special consideration is given to the participants' health care needs and to the project's affordability and applicability to other locales.

Project Setting

YAP's Organizational History and Philosophy

The University of Minnesota Youth and AIDS Projects was founded in 1989, with a mission to prevent transmission of HIV to and from high-risk youth and to provide care to youth and families living with HIV infection. The governing philosophy is that adolescents can and do make responsible health-related decisions, given appropriate resources and support. YAP programs are grounded in the belief that HIV-related services for youth must be developmentally appropriate, culturally competent, coordinated, and family-centered to be effective.

The University of Minnesota Youth and AIDS Projects adheres to a "one-stop shopping" model of care, offering the most commonly needed services at a single agency, with convenient appointments and minimal waiting times. All grant-supported services are free. Clients can easily meet various needs or transition between the different levels of care in a familiar environment, with a continuity of caregivers. The centralization of services also enables appointments to be scheduled at families' convenience and reduces logistical and administrative barriers to care.

The University of Minnesota Youth and AIDS Projects is administratively housed in the Division of General Pediatrics and Adolescent Health in the Department of Pediatrics at the University of Minnesota. The division was established in 1978 for the purposes of service, teaching, and research on behalf of adolescents. As both a university- and community-based organization, YAP intertwines service provision, research, and teaching in all aspects of programming.

The University of Minnesota Youth and AIDS Projects programs are operated by 20 salaried staff (including a research interviewer, two outreach workers, and a supervisor who are <25 years of age), six peer educators, and variable numbers of youth and adult volunteers. YAP's offices in the Loring Park neighborhood of Minneapolis include approxi-

mately 3500 square feet, and are well marked by outdoor signage, are wheelchair accessible, and are near downtown bus routes.

YAP Programs and Facilities

With federal, state, and county grant support, YAP currently sponsors three main types of programs pertaining to HIV/AIDS prevention, HIV antibody counseling and testing, and services for infected youth and their families.

Prevention. Two HIV prevention programs currently serve young men who have sex with men (YMSM). One emphasizes service, providing individual risk assessment and risk-reduction counseling, peer education, referrals to medical and psychosocial services, and longitudinal follow-up to monitor and reinforce progress. The other is a multisite research initiative to develop and test new community-level preventive interventions. To increase the capacity of other agencies, YAP also provides ongoing professional training and consultation on HIV/AIDS prevention strategies for young men who have sex with men.

Testing. The HIV antibody counseling and testing program serves the clients of YAP's prevention programs, adolescent women at risk for HIV infection who are referred by other professionals, and any adolescent and adult men and women who are the sexual and/or drug-use partners of YAP's HIV-positive clients. The service is not intended to replace public counseling and testing facilities, but is especially geared to youth who are likely to have been exposed to HIV. For the period 1992–1996, 233 persons were tested, with an overall seroprevalence rate of 2.37%. Although testing is done anonymously at YAP, the availability of on-site HIV services has enabled all of the seropositive clients to be linked with care.

HIV care. Human immunodeficiency virus-related care is available to all young men and women with HIV infection in Minnesota, and to their families. Clients also may include the HIV-positive and undetermined-status infants and children of HIV-positive adolescents. HIV-positive adolescents and their families are offered a comprehensive array of services, including case management, prevention services, HIV antibody counseling and testing, comprehensive medical care, referral to subspecialty services, emergency funds, condoms, help with entitlement programs, so-

cial support, and external referrals for clinical trials, food, shelter, clothing, educational, and vocational needs. With the exception of medical care at the University of Minnesota Hospital and outpatient clinics, all other services are available at YAP offices. Clients who have established professional relationships with other health care providers are encouraged and assisted by YAP case managers to maintain those linkages.

HIV/AIDS in Minnesota Youth

In Minnesota, health care providers and laboratories are required by law to report AIDS and non-AIDS HIV cases with identifying information to the MDH. Emergency funds for HIV/AIDS surveillance and prevention were first appropriated by the state legislature in November 1985. Federal funding for HIV-related activities from the Centers for Disease Control and Prevention began in June 1986. By January 1997, 2221 non-AIDS HIV cases and 2994 AIDS cases (including 1821 deaths) had been reported (1). Minnesota ranks 26th for the cumulative number of persons living with HIV in the United States (2).

From 1985 through 1996, 353 HIV/AIDS cases in 13–22-year-old persons were reported to the MDH (3). The epidemiology of HIV/AIDS in Minnesota youth differs from that of Minnesota adults in several important ways. As compared to adults, a larger percentage of infections in 13–22-year-old persons occurred in women (11% vs. 27%) and people of color (26% vs. 38%), and by heterosexual transmission (7% vs. 13%).

In research that led to the development of the Adolescent Early Intervention Project, Remafedi and Lauer (4) studied the cumulative survival of all 117 HIV-positive adolescents (13–21 years of age) without hemophilia, reported to the MDH through December 1992. Fourteen percent of the original sample were found to have died, mainly from well-recognized complications of AIDS. Among the deceased, the median duration of survival after HIV diagnosis was only 3 years. Cumulative survival 8 years after diagnosis was projected to be 52%. Older age at diagnosis was inversely associated with survival. Thus, despite an apparent advantage to younger age at diagnosis, cumulative survival in this adolescent cohort was found to be much shorter than expected, probably owing to delays in diagnosis and treatment.

Interviews successfully completed with 67% of known survivors revealed that HIV infection often accompanied serious preexisting psychosocial prob-

lems including running away from home (50%), being forced from home (28%), homelessness (20%), high school dropout (36%), unemployment (53%), serious substance abuse (30%), and attempted suicide (42%) (5). Relatively soon after diagnosis (median 3.5 years), 69% of persons who were aware of their laboratory results reported CD₄ counts below 500/ μ l; and a sizable portion of the sample reported HIV-related physical limitations (55%) and hospitalizations (25%). Only one third of the sample reported having "an HIV case manager"; and another 30% identified "case coordination" as an unmet need.

These observations raised concerns about local barriers to health care resulting in morbidity and premature mortality. Consequently, the local SPNS initiative was developed to provide uniform case-management services, link youth with health care early in the course of illness, and demonstrate this approach to outreach and service to other localities.

Description of the Model

The conceptual framework for the Adolescent Early Intervention Project is a novel application of standard public health disease surveillance strategies to the provision of early intervention services to HIV-positive youth. With this approach, adolescents (13–22 years of age) with HIV infection are initially identified through the existing system of mandatory name-linked reporting of HIV cases. Subsequently, the MDH adolescent early intervention specialist (AEIS) locates clients, assesses health care needs, offers information and help with partner notification, and refers them to YAP for comprehensive health care. For the duration of the project, these duties have been assumed by an experienced public health disease interventionist with a special interest in adolescent health. The program activities and the model directly meet the stated needs by providing outreach to all known HIV-positive youth soon after diagnosis and by linking them to health care systems early in the course of infection. Beyond the usual costs of HIV-related care, part-time salary support for the AEIS is the main additional expense of this model, paid by HRSA Special Projects of National Significance.

The process of locating a client begins by contacting the original reporting site, validating the available locating information, and determining whether the client has been previously informed by a physician or clinic of the HIV test result. Initial contact is attempted by telephone, when one is available to the

client and the number is known. If the telephone number is known, but there is no response to at least five calls (i.e., three during business hours and two in the evenings), the AEIS conducts a field visit to the home. If repeated (i.e., three in the Twin Cities metropolitan areas or two in Greater Minnesota) field visits are unsuccessful, an attempt is made to reach the client at the workplace, if known.

Under no circumstances will the AEIS reveal any private client data to others. If the locating information is found to be incorrect, other field techniques are used, as needed. These include the use of records from the Department of Motor Vehicles, postal service, public financial workers, schools, reporting physicians, and death certificates.

Written messages are not left for clients unless at least one field visit has been conducted and the AEIS is assured that the individual resides in the dwelling. When leaving messages for clients, the AEIS does not disclose the reason for the contact to any third party. Written messages are sent in plain security-type envelopes and do not reveal the reason for contact. A typical message might read: "Please call me as soon as possible, as I have some important information to discuss with you."

Having reached the client by telephone, the AEIS will introduce herself by name, inform the client of the personal nature of the conversation, and confirm that they are speaking privately. She confirms the client's identity (e.g., by birthdate) and identifies herself as an employee of the MDH. Thereafter, she requests permission to meet face-to-face for an interview regarding the client's experiences with health care services. The subject of HIV/AIDS is not mentioned at this time. If the client is reluctant to meet, the AEIS politely concludes the conversation in a manner which permits a possible future approach.

At the face-to-face meeting, the AEIS reintroduces herself and confirms that the client is the correct person. The client is informed of the purposes of the contact. These include assessing prior use of HIV-related services and current service needs, offering information about HIV disease and available services, facilitating linkage to comprehensive services at YAP, and providing disease intervention/partner notification services. The client is informed that participation in any and all aspects of the program is voluntary and that all information will be kept confidential.

With the client's approval, the AEIS conducts a structured interview regarding health status and needs. Thereafter, she answers questions about HIV and provides written informational materials regard-

ing HIV-related services in Minnesota. Clients who are already enrolled in medical or psychosocial services are encouraged and supported to continue existing linkages. Those persons with outstanding needs, which describes all but a few participants, are offered referral to YAP.

Also, clients are offered help with partner notification. If partner notification services are accepted, the AEIS determines the putative period of infectivity and solicits locating information for partners during that time. Clients may choose to notify partners on their own, with the help of the AEIS, or by the AEIS alone. Sexual or drug-use partners of adolescent clients can be referred to YAP for HIV prevention services and/or HIV antibody counseling and testing.

For those adolescents who accept referrals to YAP, appropriate consent for release of information is obtained to allow an exchange of identifying and locating information between the AEIS and the YAP case manager. With the client's consent, the information will be forwarded to the YAP case manager to ensure follow-up. If the client refuses to release locating information, the AEIS will arrange the appointment or provide a telephone number to reach the YAP case manager directly. Although some clients are able to visit YAP without assistance, others receive appointment reminders, transportation, and/or accompaniment, as needed.

Clients who fail to keep appointments at YAP are recontacted by the AEIS to assess and address barriers to care. At least three attempts are made during a 3-month period to facilitate access to services. At any point in the process, clients may temporarily decline help or permanently terminate contact. Finally, the AEIS is available for family visits to facilitate discussions, provide information about available community services, and help design and implement a care plan.

Although most HIV-positive youth in the state learn about YAP through this referral system, some may not, either because they are unlocatable or because their cases have not been reported to the MDH. The latter occurs for a variety of reasons, including the use of pseudonyms during testing, testing in military facilities or in another state, or clinicians' oversight. Nonreported HIV-positive youth can learn about the services at YAP through professional services networks and the Minnesota AIDSline.

At the time of enrollment at YAP, clients meet with a case manager who conducts a semistructured, comprehensive assessment of medical and psycho-

social needs. A physician is identified for youths who do not have an established provider. The clients' initial visits at YAP are an opportunity to get acquainted with the case manager. Two or three encounters may be necessary to assess health and psychosocial status. Care is taken to work at the adolescent's pace and to establish rapport before broaching sensitive issues.

All HIV-positive clients are eligible to receive the following free services from YAP: needs assessment, education and risk-reduction counseling, case management, early intervention health care, HIV antibody counseling and testing for partners, condoms, referral services, emergency funds, and transportation. The client, family members, case manager, AEIS, referral agencies, and other multidisciplinary team members collaborate in the development of a care plan, which continuously evolves with the client's needs. Beyond the provision of medical services, the plan addresses other needs related to the prevention of secondary transmission of HIV, education, vocation, housing, clothing, nutrition, mental health, substance abuse treatment, respite care, social support, recreation, finances, legal assistance, transportation, and advocacy. Client information is regularly updated at weekly case conferences that are attended by most team members.

Clients are transitioned to adult case management and health care programs at the University of Minnesota and elsewhere after the 25th birthday. This transition occurs prior to the 25th birthday if: (a) they are older than 18 years of age, (b) they have been enrolled in YAP for at least 2 years, and (c) they have demonstrated for at least 1 year emotional and social stability, the ability to maintain activities of daily living, and responsible behavior in school, employment, social, and other professional settings.

Evaluation

Preliminary results have indicated that almost everyone interviewed by the AEIS accepted case-management services. Those who did not receive services were evenly divided among persons who were unlocatable and those who refused to meet with the AEIS. Implementation of the project resulted in an increase in the proportion of youth enrolled in case-management services, as compared to pre-1992 levels (from 33% to 49%; $p = 0.14$) (6).

Interim analysis of participant interviews helps to understand the health care service needs of this population. As of February 1997, 16 male and 20

Table 1. Description of HIV-Seropositive Youth Interviewed ($n = 36$)

Age (mean, range)	21 years (17-23)
Characteristics	<i>n</i> (%)
Gender	
Males	16 (44)
Females	20 (56)
Youth of color	20 (56)
Self-identified sexual orientation	
Gay/bisexual	10 (28)
Lesbian	1 (3)
Heterosexual	25 (69)
Homeless/runaway	12 (33)
Active symptoms	
Depressed	24 (64)
Fatigue/weakness	17 (47)
Insomnia	15 (42)
Arthralgias/myalgias	14 (36)
Sinus problems	13 (36)
Headache	12 (33)
Functional impairment (Karnofsky scale)	12 (33)

female clients, ranging in age from 17 to 23 years (mean 21 years), had been interviewed by the AEIS. Different from the predominantly Caucasian population (94%) of Minnesota, the sample was overrepresented by people of color (56%; $n = 20$). Ten of the men described themselves as gay or bisexual, and most of the other male and female youth, as heterosexual. The description of this population is shown in Table 1.

More than half of the clients (56%; $n = 20$) had not graduated high school. Half were unemployed at the time of the survey, and the majority of employees ($n = 10$) were working <40 h/week. Forty-two percent ($n = 15$) reported medically related debts, and 17% ($n = 16$) of respondents presently were without means of paying for medical care.

The majority of clients (86%, $n = 31$) lived with other people, most commonly a partner ($n = 11$) and/or dependent children ($n = 8$). More than three quarters (78%; $n = 28$) reported a gross family income below the Federal poverty level, and one third ($n = 12$) of individuals considered their housing situation to be unstable.

Prior psychosocial problems were common, including inconsistent use of condoms in the past year (83%; $n = 30$), trouble with the law (50%; $n = 18$), running away from home (Table 1), and suicide attempts (28%; $n = 10$), unrelated to HIV in all but two cases. One third of clients ($n = 12$) had been confronted by a significant other as having an alcohol or drug problem.

A mean of 0.5 year had elapsed since the first seropositive HIV antibody test result and the interview with the AEIS. Typically, the results had been obtained in physicians' offices and general clinics ($n = 18$). Testing occurred less commonly in sexually transmitted disease (STD)/HIV counseling and testing sites ($n = 9$) and the mandatory testing programs of the military, prisons, Job Corps, or plasma centers ($n = 5$). More than a quarter of respondents (28%; $n = 10$) believed that they had not received a good explanation of results.

Active symptoms, reported by a third or more of the sample, are listed in Table 1. One third of clients reported some degree of functional impairment on the Karnofsky scale, a measure of physical performance (7). Two thirds ($n = 24$) had consulted a physician about HIV care, and almost half of them ($n = 11$) had had antiretroviral treatment prescribed. Fewer than a third of the sample (31%) reported having a case manager, and only 20% ($n = 7$) had received mental health services in the past year. From a list of 38 different services, one half or more of the clients reported needing advocacy/case coordination (75%; $n = 25$), clinical trials of experimental therapies (56%; $n = 20$), vocational training (50%; $n = 18$), and access to entitlement/eligibility programs (50%; $n = 18$).

Case managers recorded 4494 contacts with the 27 clients enrolled at YAP. A total of 4578 services were recommended, of which 3387 (74%) were accomplished. Eighty-seven percent of completed services were provided by YAP, and 13%, by other organizations. The largest categories of completed services were case coordination ($n = 2095$); access to entitlement programs and social services for persons with HIV/AIDS ($n = 520$); primary and subspecialty medical and dental care ($n = 361$); health education and risk reduction ($n = 268$); and mental health and chemical dependency services ($n = 76$), accounting for 98% of all services that were provided or facilitated by case managers.

Conclusions

The experience of the Adolescent Early Intervention Project chronicles the evolving epidemiology of HIV/AIDS in Minnesota and the United States. During the 1990s, an increasing proportion of HIV/AIDS cases have occurred among women, people of color, and heterosexual persons. These trends have been most pronounced among youth, among whom young women of color now constitute the largest subpopulation reached by this adolescent SPNS pro-

gram project, even in a state whose population is predominantly Caucasian.

Despite the changing demographic profile of HIV-positive youth, the types of problems they experience are not substantively different from earlier years in the epidemic. Today, as before, HIV in adolescents occurs against a backdrop of serious psychosocial difficulties (5).

Given the urgency of these concerns, it is not surprising that asymptomatic infections in adolescents frequently go undetected (5). Fewer than a third of the youth were diagnosed in HIV counseling and testing sites, and more than twice as many infections were detected in clinics or mandatory testing programs. Although interviews were held relatively soon after diagnosis, a large percentage of clients reported HIV-related symptoms and/or physical limitations. Most of the common symptoms could be affective, rather than organic, in nature. However, relatively few clients had obtained mental health or case management services before their involvement with this initiative (5).

To provide needed services, the design of the Adolescent Early Intervention Project has successfully capitalized on the preestablished system of name-linked reporting of HIV cases to the MDH. This approach could be easily and inexpensively adapted to other states with similar HIV disease surveillance mechanisms. Linking infected individuals to systems of care is a convenient and compassionate extension of the work of disease intervention specialists, who already contact clients to offer voluntary partner notification services. Since clients are required to give written consent for the release of any identifying information, the project does not threaten the confidential relationship between health departments and clients.

Beyond the usual costs of disease surveillance and partner notification programs, this initiative requires the additional time and effort of the disease intervention specialist to link clients with systems of care. Other requisites are a collegial relationship between local public health and health care systems and the ability of health care systems to accommodate the influx of needy clients. This model of care for adolescents also may be helpful to other populations who face barriers within traditional health care settings.

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