BUILDING A SYSTEM OF COMMUNITY CARE FOR PEOPLE WITH HIV: 
THE CHICAGO EXPERIENCE


AIDS FOUNDATION of CHICAGO
August 1999

The mission of the AIDS Foundation of Chicago is to provide leadership in marshalling public and private resources to care for people living with HIV/AIDS and to prevent the further spread of the epidemic. We pursue this mission through advocacy, fundraising, grantmaking, and service coordination/coalition-building.
THE AIDS FOUNDATION OF CHICAGO...
BRINGING COMMUNITIES TOGETHER IN THE FIGHT AGAINST AIDS

Established in 1985 by civic leaders and health professionals to coordinate local response to the epidemic, the AIDS Foundation of Chicago (AFC) is the largest private sector AIDS organization in the Midwest. Since its founding, AFC has worked to develop and support a comprehensive system of HIV care and prevention, bringing together public and private resources, advocating for sound and compassionate public policy, and coordinating the activities of AIDS service providers. Leading the fight against the epidemic in metropolitan Chicago, the AIDS Foundation of Chicago has achieved significant progress in five key areas:

- Providing funding, training, and technical support for AIDS care and prevention programs
- Developing and supporting complex HIV service delivery systems requiring a high level of inter-agency cooperation and trust
- Working with policy makers at all levels of government to increase public funding for AIDS programs and services and to protect the rights of people living with HIV/AIDS
- Fostering effective collaboration among AIDS service providers
- Increasing private sector support for AIDS programs and services

PROVIDER COLLABORATION PROMOTES EFFECTIVE USE OF RESOURCES

All AIDS Foundation of Chicago programs involve community partnerships with organizations working on the front lines of AIDS care and prevention. At the heart of this approach is AFC's 135-member Service Providers Council. The only AIDS coalition of its kind in the entire country, the SPC includes both large and small agencies operating throughout metropolitan Chicago. SPC member agencies come together at AFC with staff support from the Foundation to collaborate on a wide range of service planning and delivery, advocacy, and training initiatives.

GRANTMAKING PROGRAM ENCOURAGES INNOVATION AND SUPPORTS AGENCY CAPACITY-BUILDING

The AIDS Foundation of Chicago is the largest source of private philanthropic support for AIDS-related programs and services in the Midwest. Since 1988, AFC has awarded over $8.5 million in private funds to local agencies conducting HIV care, prevention, public education, and advocacy projects. Grantmaking priority is directed to community-based organizations in under-served areas, especially those governed by and serving people of color. Increasing private philanthropy for AIDS-related programs and services is an important part of AFC's mission. AIDS Foundation grants are entirely supported by the Foundation's own aggressive fundraising efforts.

PROTECTING THE RIGHTS OF PEOPLE WITH HIV IS A TOP PRIORITY

The AIDS Foundation of Chicago is Illinois' leading advocate for people living with HIV/AIDS and the organizations on which they depend. Working with policymakers at all levels of government, AFC has fought successfully for increased public funding for AIDS care and prevention programs, for expanded AIDS services, and for an end to discrimination against people affected by the epidemic. Strategies include lobbying, constituent organizing, coalition work, media campaigns, and participating in government planning bodies and advisory groups. The Foundation has built an extensive statewide network of hundreds of individuals and organizations that can be mobilized quickly by fax and phone to generate calls and letters to public officials.

BUILDING A COMPREHENSIVE SYSTEM OF HIV CARE IS THE OVER-ARCHING GOAL

Since 1989, the AIDS Foundation of Chicago has taken responsibility for the administration, ongoing development, and evaluation of the coordinated HIV care management system described in detail in this report. The Foundation also serves as lead agency for the Cook County HIV Care Consortium, responsible for identifying unmet needs for HIV care in Cook County and for distributing and managing federal funds allocated by the Illinois Department of Public Health for primary medical care, housing, substance abuse, food, mental health treatment and other services.

Dear Friends and Colleagues:
The Chicago metropolitan area is home to an estimated 30,000 people living with HIV and AIDS. It is also home to the nation's only coordinated HIV case management system—a remarkable venture in community planning and service delivery known formally as the Northeastern Illinois HIV/AIDS Care Management Cooperative. Led by the AIDS Foundation of Chicago, the care management system extends across a nine-county region and involves 55 local agencies in ensuring that over 5,000 people living with HIV/AIDS have access to medical care, housing, food services, emergency financial assistance, transportation and other needed services.

More than ten years have passed since the AIDS Foundation of Chicago took the first steps toward development of a coordinated HIV case management system in 1988. Meanwhile, the epidemic has marched relentlessly through City neighborhoods and into the surrounding suburban and rural counties—challenging the ability of local health and social service providers to respond with the limited resources available. In Chicago, as in the nation as a whole, the face of the epidemic has changed significantly over the past ten years. AIDS is increasingly prevalent among African-Americans, Latinos, women, and injection drug users. And, while advances in medical treatment have reduced the number of people dying from AIDS-related illnesses, the number of people living with HIV continues to grow.

In the pages that follow, we mark the tenth anniversary of Chicago's coordinated HIV care management system by telling the story of the system's growth and development from a modest experiment involving three agencies and four case managers to a mature inter-agency collaboration unique in the nation and in the history of the AIDS epidemic. As you will see, the story has three themes—commitment, collaboration, and shared values—and many players: people living with HIV, their caregivers, the AIDS Foundation of Chicago, community service providers, and government and private funders. It is a story about service, leadership, compassion, diversity, innovation, and making resources stretch as far as possible. It is a story that continues to evolve. Join us as we look back with pride at our accomplishments and ahead with determination to face the challenges yet to come.

Mark Ishaug
Executive Director
AIDS Foundation of Chicago

Freddie Shufford
Chair
Case Management Governance Committee

The AIDS Foundation of Chicago gratefully acknowledges the Chicago Department of Public Health's support for this project.
It all began ten years ago. Resources were scarce, services were limited, and the epidemic was spreading rapidly. A group of providers and consumers came together to try to figure out how best to respond to the needs of the growing number of people with HIV trying to navigate Chicago’s fragmented health and human service delivery system.

In 1989, with funding from the federal Health Services and Resources Administration (HRSA), the Service Providers Council of the AIDS Foundation of Chicago convened a task force to review the status of HIV case management in the Chicago area. At the time, relatively little in the way of medical treatment was available. Those who sought care often did so only when they became very ill, and social support to counter AIDS stigma was critically important. Given the complex needs of those affected, the mixed array of case management services being provided, and the likely waste of resources due to lack of coordination, task force participants agreed that an ongoing working group should develop a model for an expanded, coordinated, area-wide HIV case management system.

The model that emerged over the following months of discussion and debate called for a consortium of case management providers linked by central administration and support and governed by providers and consumers. The model developed by the Service Providers Council working group placed case management firmly within the framework of client advocacy: it was conceived from the beginning as a way to open doors for people with HIV to help them gain access to the widest possible array of needed services and available resources.

In July 1989, the proposed consortium was formally established as the Northeastern Illinois HIV/AIDS Case Management Cooperative. Administered and supported from the beginning by the AIDS Foundation of Chicago, the system began with four case managers at three local agencies. Over the next two years, it doubled in size — to eight case managers. AFC also received funding to hire a case management coordinator, develop training programs, and establish a central information and referral resources database.

In 1991, funding appropriated by Congress for the new Ryan White CARE Act began to flow to the Chicago metropolitan area. A significant portion of early CARE Act revenues were allocated to further develop and expand case management services, and a period of rapid growth ensued. From September 1991 to September 1994, the number of funded case management positions in the AFC-administered system grew from eight to 82 and the number of agencies involved in the network grew from four to over 30. Today, 159 case managers and 55 agencies are funded by the AIDS Foundation to provide case management services across the metropolitan area.

Locating case management services in a wide variety of agencies throughout the metropolitan area means that people living with HIV can receive care close to home in a setting that best meets their individual needs.

The agencies funded to provide case management services in Chicago are as diverse as the clients they serve. Case management providers are geographically dispersed throughout the metropolitan area. Both large and small, they include housing programs, social service agencies, substance abuse treatment providers, health centers, hospitals, and outreach groups. Some serve only people with HIV/AIDS, while others provide HIV case management services as part of a much larger mission.

The case management system’s core values were identified early. Among the most important are a central focus on clients, geographic accessibility, cultural sensitivity, responsiveness to the special needs of specific populations, and equitable allocation of resources across the metropolitan area.

Guided by these core values, the case management system has grown in complexity as well as size. In 1990, Illinois obtained a waiver from the federal government enabling the state to receive Medicaid reimbursement for in-home services provided to people seriously disabled by HIV disease. AFC was asked to administer the program, which now provides case management and homemaker assistance to over 700 people each year. In 1992, the AIDS Foundation assumed responsibility for establishing and administering a central transportation system for case managed clients, and in 1994, for managing and distributing funds available for emergency financial assistance. In 1996, following an extensive community planning process resulting in the metropolitan area’s first AIDS housing plan, the AIDS Foundation took on central administration of resources available for long-term rent subsidies for people with HIV.

Integrating homemaker assistance, transportation services, emergency financial assistance, and long-term rent subsidies with case management has made these services more accessible to people living throughout the metropolitan area, while reducing administrative costs and establishing high standards of client care and agency performance. Adding services to the case management matrix has resulted in a truly comprehensive, coordinated system of HIV care.

Chicago’s HIV case management system combines local agency responsiveness, sensitivity and flexibility with the benefits of central administration and support. A central client registry enables the AIDS Foundation to track service utilization and avoid costly duplication. Written policies and procedures are regularly reviewed and updated by the Case Management Governance Committee. Agency performance is monitored by AIDS Foundation staff. Case managers receive in-depth orientation and ongoing training.

Consumers participate on the Case Management Governance Committee and provide critical feedback through client satisfaction surveys and focus groups.

As the case management system has expanded and become increasingly complex, the AIDS Foundation of Chicago continues to work in partnership with providers and consumers to identify and fill gaps in service, monitor the system’s effectiveness, keep case managers current with the changing epidemic, and deliver high-quality services that truly meet the needs of people living with HIV.
HOW THE CASE MANAGEMENT SYSTEM WORKS: SERVICE AND SUPPORT

Linking people with needed resources and services is the goal. Simply stated, case management is the process of ensuring that people living with HIV/AIDS have access to the services they need to maintain optimal health and live as independently and safely as possible. Like others with chronic illnesses, people with HIV must navigate a confusing and fragmented health and social service delivery system. Locating and obtaining access to high-quality medical care and other needed services is often difficult, and can be even more so for those who are poor, live in under-served communities, are isolated or cut-off from family and social support, speak a language other than English, use injection drugs, or otherwise need additional assistance and support. Over the past 10 years, Chicago’s coordinated HIV case management system has linked more than 15,000 people living with HIV and AIDS with primary medical care, AIDS drug assistance, and other services leading to improved health and quality of life.

Since the creation of the Chicago Metropolitan Area’s case management system in 1988, the AIDS Foundation has been the central agency responsible for coordination and support. Actual case management services are provided by community-based agencies identified and funded by the AIDS Foundation of Chicago. As lead agency, the AIDS Foundation:

- Establishes contractual agreements with funded agencies and reimburses them for case management services provided;
- Develops and administers policies and procedures aimed at achieving effective service delivery and fair allocation of resources;
- Manages and ensures equitable access to funds for an integrated group of core client services including case management, transportation, emergency assistance, and rent subsidies;
- Maintains a central client registry to prevent duplication of services and monitor service utilization;
- Operates a staffed, bilingual information and referral service for clients and case managers;
- Monitors program utilization and effectiveness through a continuous quality improvement program; and
- Supports case managers and funded agencies and promotes good service delivery through an extensive training and technical assistance program.

The over-arching goal of all systems coordination activity is to ensure high quality, consistent service delivery to people living with HIV throughout the Chicago metropolitan area — while reducing administrative costs and avoiding duplication of service.

The Northeastern Illinois HIV/AIDS Case Management Cooperative defines case management as “a standardized process of intake, assessment, planning, service coordination, referral, follow-up, and advocacy through which the multiple service needs of people affected by HIV disease can be met.”

Each person requesting case management services is assigned a single case manager, who assesses the client’s needs and helps him or her obtain ongoing services. This individualized approach is grounded in the belief that people living with HIV/AIDS are best served in a sustained, empowered relationship with another individual. Respect and support provide the foundation for the client/case manager relationship, which is dynamic, with the intensity and frequency of service determined jointly by client and case manager.

Case managers are knowledgeable about HIV and related health and human services available in the Chicago metropolitan area. Using this knowledge, case managers help people with HIV who are eligible apply for Social Security disability income, Medicare, AIDS drug assistance and other income support and health care programs. They make sure clients are receiving appropriate HIV medical care, help clients find safe and affordable housing, and assist clients in gaining access to a whole range of other services including home delivered meals, mental health care, substance abuse treatment, and legal assistance. Once a service plan is established and referrals made, case managers stay in regular touch and provide ongoing support — following up on linkages made and providing new referrals when needed. Each case manager carries a client case load of 30-60 individuals, with case load size varying according to clients’ severity of illness and intensity of service need.

In addition to ongoing needs assessment, referrals, and support, case managed clients can obtain other key services directly through the case management network.

In order to ensure equitable access to limited resources by people with HIV throughout metropolitan Chicago, some HIV services are available only through the coordinated case management system. Clients who need and are eligible for emergency financial assistance, subsidized transportation to HIV-related medical and social service appointments, long-term rent subsidies, and ORS homemaker assistance are linked directly to these services by case managers. Funds for emergency financial assistance, client transportation, and rent subsidies are administered by the AIDS Foundation of Chicago, which establishes system-wide policies for eligibility and utilization of such funds. Given that available resources are limited and cannot meet the needs of all people living with HIV, services are provided first to those most ill or disabled by HIV and to those with the greatest financial need.

“Chicago’s case management system is a national model of provider collaboration. As AIDS reaches new populations and communities, the AIDS Foundation and its partner agencies ensure that those most affected and most in need have access to a wide array of health and support services.”

—Frank Oldham, Jr., Assistant Commissioner Division of STD/HIV/AIDS Chicago Department of Public Health

Continued on next page
Case management services in metropolitan Chicago are provided by a network of community-based provider agencies. The AIDS Foundation of Chicago identifies and funds these agencies, who in turn, hire case managers to provide direct services to clients.

While the case management system is centrally administered and coordinated, actual case management services are delivered by individuals working in community-based agencies located throughout the racially, ethnically, geographically, and economically diverse Chicago metropolitan area. Case management agencies serve every HIV-affected population group, including people of color, gay and lesbians, women and children, injection drug users and their partners, and suburban residents. From the inception of the system, the AIDS Foundation has actively identified, recruited, and supported community-based agencies able to provide high-quality case management services to medically under-served populations, and has helped numerous grassroots and community-based agencies strengthen administration and expand service capacity.

The case managers employed by funded agencies are as diverse as the clients they serve. Individuals come to this work from a wide variety of educational backgrounds and occupational fields. Case managers are women and men, gay and straight, old and young. They represent many different racial and ethnic groups. Throughout the history of the case management system, a significant number of case managers have themselves been people living with HIV.

Individuals seeking case management services can enter the system in many different ways. The AIDS Foundation and its partner case management agencies work together to build awareness of the case management system among HIV+ individuals and other health and human service providers, and referrals come from many different sources. Clients referred for or expressing interest in case management services can begin the process at any of the 55 funded case management agencies or by telephone with the AIDS Foundation of Chicago: actual intake of those determined eligible and wishing to enroll is conducted by staff at the case management agency from which the individual will receive services. The AIDS Foundation of Chicago maintains a confidential computerized central registry of all clients receiving case management services. The registry ensures that clients are assigned a single case manager, and enables AFC to monitor utilization of case management and related services. Demographic and referral information maintained in the registry for each client is updated every six months as case managers review client service plans and linkages made and re-assess client needs. Over 15,000 client records have been maintained in the central registry since it was established without a single breach of confidentiality.

Agencies funded by the AIDS Foundation to provide case management services do so according to standard operating procedures and quality assurance policies established by the Case Management Governance Committee.

The Governance, a standing committee of AFC’s Service Providers Council, is a 15-member body broadly representative of both funded case management agencies and HIV-affected populations in the area. Comprised of agency program directors, case management supervisors, case managers, and consumers, the Governance includes city and suburban providers, gay and lesbians, people of color, and individuals serving women, children, substance users, hemophiliacs, and other affected communities. The Governance meets monthly at the AIDS Foundation. In addition to its responsibility for ongoing policy development, the Governance provides general oversight of the case management system, identifies service gaps and sets priorities for system expansion, establishes the annual case manager training calendar, reviews results of client and agency satisfaction surveys, and participates in funded agency site visits.

Extensive ongoing program and administrative support for all funded agencies is a hallmark of the coordinated case management system.

The AIDS Foundation of Chicago’s case management system staff team includes several Program Associates, each of whom serves as principal liaison to a cluster of case management agencies. Program Associates make case management referrals, help case managers link clients to appropriate services, process requests for transportation services and emergency financial assistance, and provide consultation on case management issues. They also convene and staff regional case management networking meetings, conduct agency site visits, and handle client grievances and complaints about case management service. AFC fiscal and administrative staff are available to provide technical assistance to funded agency staff in these areas of expertise.

“...The case management system is the critical link between people living with HIV and the services they need. As the major agency providing food and nutrition services to people with HIV, we work closely with the AIDS Foundation and case managers to meet the needs of clients throughout Chicagoland.”

—Deborah Hinde, President and CEO, Open Hand Chicago
Over the past ten years, Chicago’s coordinated HIV case management system has grown from three agencies on Chicago’s north and west sides to a network of 55 agencies located in and serving every section of the city plus the nine-county suburban and collar county region. Agencies that provide case management services to people living with HIV serve all affected population groups — including people of color, men who have sex with men, women and children, injection drug users and their partners, and inmates in the criminal justice system. In adding providers to the network, the AIDS Founda- tion has sought to concentrate services in areas most affected by the epidemic while maintaining geographic access throughout the region.

CHICAGO
1. Asian Human Services Inc.
2. Bonaventure House
3. CALOR, a Division of Anchor Center
4. CORE Center
5. Catholic Charities
6. Cermak Health Services
7. Chase House - Ascension Respite Care Center
8. Chase House - St. Margaret
9. Chase House - St. Stephen
10. Chicago House & Social Service Agency
11. Chicago Women’s AIDS Project
12. Children’s Memorial Hospital
13. Children’s Place Association
14. Circle Family Care
15. Come Alive Social Services
16. Community Counseling Center of Chicago
17. Community Supportive Living Systems
18. El Rincon
19. Erie Family Health Center
20. HRDI Inc.
21. Hemophilia Foundation of Illinois
22. Howard Area Community Center
23. Howard Brown Health Center
24. Interventions
25. Lawndale Christian Health Center
26. Live Ministries
27. Michael Reese Hospital
28. Minority Outreach Intervention Project
29. New City Health Center
30. New Phoenix Assistance Center
31. Pilsen - Little Village Mental Health Center
32. President Hospital of Cook County
33. Roseland Community Hospital
34. Sinai Health Systems
35. South Shore Hospital
36. South Side Help Center
37. T.A.S.C.
38. Test Positive Aware Network
39. The Woodlawn Organization
40. The Rafael Center
41. University of Chicago Children’s Hospital
42. University of Illinois, CDP-North
43. University of Illinois, CDP-Northwest
44. University of Illinois, CDP-South
45. University of Illinois, Mile Square Health Center
46. Urban Life Line
47. West Side Clinic at Bethany
48. Wicker Park Clinic
49. AIDS Ministry of Illinois
50. BE-HIV
51. Catholic Charities of Lake County
52. Community Response
53. Cook County Dept. of Public Health
54. DuPage County Dept. of Public Health
55. Open Door Clinic

CHICAGO METROPOLITAN AREA

AGENCIES PROVIDING HIV CASE MANAGEMENT SERVICES IN CHICAGO: MAPPING THE REACH AND DIVERSITY OF CHICAGO’S COORDINATED CASE MANAGEMENT SYSTEM
In its most recent needs assessment process, the Chicago and Cook County HIV Services Planning Council estimated that 90% of those living with AIDS and between half and 85% of those living with HIV need case management services during the course of their illness. Those who will particularly benefit from case management services include individuals who are socially isolated, have limited financial resources, have special conditions such as hemophilia or substance addictions, or otherwise face personal or environmental obstacles impeding access to basic health and human services.

On August 1, 1999, a total of 5,379 individuals were receiving services from the case management system. Some 41% of clients enrolled in the case management system are diagnosed with AIDS — indicating that the system is reaching over 30% of all those currently reported living with AIDS in the Chicago metropolitan area. The demographic profile of all those enrolled reveals that the system is also reaching those most in need of case management services and most likely to benefit from services: more than half have annual incomes under $5,000; 84% have incomes under $10,000; and only 10% are covered by private medical insurance. Forty-three percent had no source of payment for health care at the time they were first enrolled. Sixty one percent of all current clients are African-American, 15% are Latino, and 29% are women.

“When I first found out I was HIV+, I didn’t know where to turn. I was scared and overwhelmed. I called the AIDS Foundation and got a case manager the next day. He helped me find medical care and housing assistance, and now I am learning to live with HIV.”

—Manuel M., age 34
TRAINING...
THE KEY TO HIGH QUALITY CLIENT SERVICES

EXTENSIVE, ONGOING IN-SERVICE TRAINING IS ONE OF THE HALLMARKS OF CHICAGO’S CENTRALIZED CASE MANAGEMENT SYSTEM.

Training provides the framework for orienting, integrating, and building the skills of the very diverse corps of case managers working in agencies with different levels of experience in AIDS care. In addition to providing case managers with practical information that helps them do their jobs effectively, training offers peer support and fosters the development of a common language and values among case managers as a group. All training programs are designed to reinforce the core values comprising the foundation of HIV care management practice — being client-centered and life-focused, focusing on client strengths, and striving to maintain autonomy, respect, compassion, and flexibility.

The AIDS Foundation of Chicago began developing and offering specialized training for HIV case managers very early in the system’s history. Today, AFC sponsors a wide array of programs aimed at helping both experienced and new case managers develop and improve key skills and provide the highest level of service to people living with HIV and AIDS. While all programs are open to all case managers in the system, each case manager must attend at least 12 separate training sessions annually, and some programs are mandatory.

NEW CASE MANAGERS RECEIVE IN-DEPTH ORIENTATION.

All case managers are required to attend a 32-hour new case manager orientation program. First introduced in 1996, this intensive introduction to the system and basic skills-building program is offered quarterly and limited to a maximum of 25 people per series to ensure maximum interaction and participation. Case managers learn about the overall HIV/AIDS case system in metropolitan Chicago and how to refer clients to basic services and help those who are eligible obtain income support, Medicaid coverage, AIDS drug assistance, rent subsidies, and transportation assistance. The series also covers core case management functions (screening, intake, assessment, service planning, record-keeping, and re-assessment), and topics like crisis intervention, client confidentiality, consultation, ethics and professionalism, and opportunities for ongoing support and training. A “mini-orientation” session is provided for case managers entering the system between quarterly programs.

TRAINING FOCUSES ON BUILDING CASE MANAGERS’ SKILLS.

The AIDS Foundation has sponsored monthly large group skills-building training sessions for case managers since 1991. Most presentations feature guest speakers, and HIV treatment updates are provided at regular intervals. Each case manager is required to attend at least six of the 12 skills-building sessions offered each year. Popular topics have ranged from HIV medications adherence to current issues for women and children with HIV and from cultural sensitivity to how to enroll clients in AIDS drug trials.

REGIONAL NETWORKING HELPS CASE MANAGERS IDENTIFY LOCAL RESOURCES TO MEET CLIENT NEEDS.

Case managers are required to attend bi-monthly small group meetings organized by region and facilitated by case managers from that region along with AIDS Foundation staff. These meetings, held at different agencies, give case managers the opportunity to discuss complex issues in a small group setting, network, and share resources and referral information specific to each region. They also provide an opportunity for AFC staff to brief case managers on changes in system policies and procedures.

BENEFITS CLINIC KEEPS CASE MANAGERS CURRENT WITH GOVERNMENT PROGRAMS.

Nearly two-thirds of clients receiving case management services rely on some sort of government assistance, e.g., Medicaid or Medicare, during the course of their illness. Recognizing case managers’ need to be knowledgeable about these resources and to keep current with changes in eligibility criteria, application requirements, and the scope of benefits, in 1996 AFC initiated a monthly two-hour “benefits clinic” facilitated by the director of the AIDS Legal Council of Chicago. A typical clinic session includes a step-by-step discussion of how to proceed in specific cases, including detailed review of necessary forms and documentation and how to support the case for eligibility. While attendance is not mandatory, the clinic is very popular among case managers at all levels of experience.

INDIVIDUAL CLINICAL CONSULTATION IS ALSO AVAILABLE.

One-on-one consultation with a licensed clinical psychologist experienced in HIV-related issues is available to any case manager in the system upon request. Case managers can use this service to discuss clinically challenging cases as well as their own emotional responses to working with clients.

SUPERVISOR TRAINING OFFERED FOR PROGRAM MANAGERS.

From time to time, the AIDS Foundation also sponsors special training programs for case management supervisors, most of whom are social workers or nurses in agencies employing more than one HIV case manager. Supervisor training programs are planned by the Case Management Governance Committee.

“The AIDS Foundation case management system sets the standard for excellence. Well-trained, committed case managers make it possible for people with HIV to obtain the services they need to maintain health and independence.”

—Ann Hilton Fisher, Executive Director, AIDS Legal Council of Chicago
ASSURING QUALITY AND MEASURING THE SYSTEM’S EFFECTIVENESS

For the first several years of the coordinated case management system’s history, the AIDS Foundation of Chicago’s top priority was expanding access to services. At the epidemic spread throughout the metropolitan area and more people needed and sought HIV case management, new agencies and case managers were added to the network to meet increased demand. As the system developed and became much larger and more complex, attention increasingly turned to the task of how to assure the delivery of consistent, high-quality services across a wide spectrum of providers and geography.

Working with the Case Management Governance Committee and a consultant experienced in developing health care certification and quality assurance programs, in 1995 the AIDS Foundation undertook development of a continuous quality improvement (CQI) program for the coordinated case management system. The process, which took more than a year, was driven by two fundamental principles: that people with HIV/AIDS deserve high quality health and social services designed to meet their individual and collective needs; and that a voluntary commitment to quality by HIV/AIDS service provider agencies is essential. Funded case management agencies and consumers participated in all phases of developing the CQI program, which was piloted tested at 20 providers and has been operating system wide since April 1996. The extensive case manager training program described in detail elsewhere in this report is a cornerstone of the CQI program.

Systematic review of funded agency performance is an ongoing process involving AFC staff, the Case Management Governance Committee, and funded agencies. Key elements used to determine whether agencies are meeting performance standards and should continue to receive funding include review of monthly narrative and statistical reports and reimbursement requests; annual agency site visits including in-depth review of case management client records; post-site visit technical assistance, if needed; regular review by AFC staff of case manager and agency case loads; ongoing review of compliance with direct emergency assistance and transportation policies and procedures; and results of annual client and agency satisfaction surveys. It is AIDS Foundation policy to renew funding annually for those agencies that demonstrate their continuing ability to provide case management and related services in accordance with established policies and procedures, meet agreed scopes of service, and otherwise comply with contract requirements. If deficiencies are found at any time during the contract year, AFC staff work with funded agency staff to correct them.

ANNUAL SITE VISITS MONITOR PROGRAM EFFECTIVENESS

Each and every agency funded to provide case management services receives an annual in-depth site visit conducted by AIDS Foundation staff and members of the Case Management Governance Committee. Site visitors meet face to face with case managers, supervisors, and agency program directors to discuss program performance; and AIDS Foundation program staff review client charts to assess compliance with case management policies and procedures. Where indicated, AFC administrative staff also attend site visits to review agency financial procedures and records. Any problems identified are addressed in a written plan. AFC provides technical assistance and consultation to agencies who need such help.

Clients provide ongoing feedback and give the system high marks.

For the past three years, the AIDS Foundation has conducted an annual survey seeking feedback from HIV case management clients about the quality and effectiveness of the services they receive. The annual client satisfaction surveys are distributed by case managers, but are completed in confidence by clients and mailed back anonymously to be tabulated by an independent agency — the Metropolitan Chicago Information Center. Several hundred clients elect to complete the questionnaire each year — an impressive response rate that has averaged 25%.

The client satisfaction survey elicits responses in several areas. Clients are asked to rate case managers’ professionalism, accessibility, respect for privacy, and responsiveness, as well as the effectiveness of services provided. A series of open-ended questions asks each client to identify specifically “what your case manager is doing right,” “how services can be improved,” and “what other services you need at this time.”

The surveys do indicate the need for better “marketing” of case management services: clients express less satisfaction with the ease of finding case management services than they do with the services themselves.

Agencies rate AFC on systems coordination.

An annual anonymous survey of funded agencies’ satisfaction with the services they receive from the AIDS Foundation of Chicago has also been conducted for the past three years. This survey, which is intended to assess and improve AFC contract administration performance, asks agencies to rate the knowledge, helpfulness, and accessibility of AFC program and administrative staff and the timeliness and ease of the reimbursement process. Agencies are also invited to comment on AFC technical assistance, case manager training, and general contract administration activities.

Like the client satisfaction survey, the agency survey draws a high response rate and documents generally high levels of satisfaction. In the most recent survey, 80-90% of agencies responded very favorably or favorably to questions regarding AFC staff helpfulness and responsiveness and the timeliness of reimbursement, and 100% of respondents rated AFC technical assistance favorably.
As Chicago’s coordinated HIV case management system marks its tenth anniversary of providing high-quality, responsive services to people living with HIV and AIDS, the AIDS Foundation of Chicago and the Case Management Governance Committee are grappling now with significant challenges facing the system in the period ahead.

- Advances in medical treatment have significantly reduced AIDS mortality. As new people continue to become infected, however, the number of people living with HIV continues to grow — and the demand for case management services continues to increase.
- As has been true for the past several years, the epidemic increasingly affects those on the margins of society — people of color, substance users, the very poor, the homeless — those most likely to need and benefit from case management services, and to have multiple, complex service needs.
- Changes in the health care industry — Medicaid reform, managed care, cost caps, and shrinking reimbursement rates — strongly favor “gatekeeping” models of case management over the “service enabling” Chicago model.

Ensuring that limited case management resources continue to follow the demographics of the epidemic, adapting services to the changing realities of living with AIDS, keeping service quality and client responsiveness high, and documenting the effectiveness of the Chicago model in a managed care environment are top priorities for the immediate future... and critical for the system’s long-term survival.

The first steps have already been taken.

- In 1999, five new case management providers serving Chicago’s south and west sides were funded for the first time. These agencies will increase service capacity in historically underserved communities, and are expected to bring as many as 500 new clients into the system.
- The reach of HIV case management in correctional facilities and for soon-to-be-released inmates will be expanded in the coming year.
- The Case Management Governance Committee has developed and recently adopted a new “acuity scale” assessment tool that will help determine the intensity and frequency of case management services needed by each client, and enable case managers to maintain more balanced case loads and serve more individuals.
- A study examining case management outcomes is being designed and will soon be piloted by the Midwest AIDS Training and Education Center.
- The Case Management Governance and the Service Providers Council’s Medical Primary Care Committee are developing strategies to further strengthen linkages between case management and primary care providers in order to ensure a truly integrated service delivery system.

These initiatives, and others being developed, are built on the foundation of commitment, collaboration, and shared values that have shaped the history of Chicago’s coordinated case management system from its inception until today. They will help ensure that the system continues to meet the needs of people living with HIV and AIDS into the next century.

If you think you might benefit from HIV case management services, or want more information, call the AIDS Foundation of Chicago at 312.922.2322.