

**Strengthening New York's**  
**Special Needs Plans**  
**for People with HIV/AIDS**

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*JUNE 2005*

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Director of Health Policy



GAY MEN'S HEALTH CRISIS

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# Executive Summary

HIV Special Needs Plans (SNPs) mark a significant change in the way HIV care is delivered in New York State. After two years of SNP enrollment, stakeholders, including health plans, medical providers, the HIV community, and the City and State, must work together to evaluate the program and assure that quality care is provided to people living with HIV/AIDS. SNPs must succeed on a smaller scale, and in the context of voluntary enrollment, before any attempt is made to implement mandatory enrollment for the 65,000 HIV-positive Medicaid beneficiaries in New York State.

One of the most important tenets of Gay Men's Health Crisis's mission is to help people with HIV maintain and improve their health and independence. If they reach their potential, SNPs are designed to do just that. This report, which analyzes the first two years of SNP implementation, is designed to help the HIV community better understand the SNPs and influence their ongoing roll-out. The SNP model contract, the document outlining SNP benefits and health plans' responsibilities to SNP enrollees, provides the framework for "tests for success," areas that are important to a successful voluntary SNP program. As the plans become fully integrated into New York's system of managed health care and increasingly become an alternative to fee-for-service Medicaid, it is important to determine whether the plans are meeting benchmarks set forth in the SNP model contract. Based on the contract, these "tests" represent the most important elements of a successful managed health care plan for people living with HIV/AIDS:

- Outreach and education: Are the SNPs and New York State reaching out to potential members? How are they educating consumers about the plans?
- Enrollment: What are clients' enrollment experiences like?
- Continuous care: Are people getting the care they need while they are transitioned to a SNP?
- Case management and care coordination: Is case management working? How? How are members' clinical and social needs coordinated?
- Accountability for high quality care: Are enrollees receiving quality care in their SNP?

Based on analysis of available data, information provided by SNP stakeholders, review of the SNP model contract, and interviews with a small sample of SNP enrollees, the following recommendations are made. SNPs should not become mandatory until these are achieved.

### ***To increase public awareness of SNPs:***

- Increase state and city funding for SNP consumer education and production of SNP advertising materials.
- Utilize new, culturally diverse avenues to promote SNPs, including SNP health fairs at locations where people with HIV/AIDS congregate, and mailings to all current Medicaid beneficiaries.
- Work directly with community-based organizations to increase front line worker knowledge of SNPs.
- Emphasize the difference between SNPs and mainstream managed care, and highlight the enhanced benefits in the SNP model.
- Ensure consumers understand that SNPs are voluntary, and they have a choice of whether or not to enroll. Potential enrollees should always be told that they have a choice of plans.

### ***To ensure continuous care:***

- Collect and publish data on whether or not SNPs are meeting their contractual obligations to: enroll people in timely way; assign a primary care provider and case manager within 30 days; ensure enrollees are receiving continuous care; and assess enrollees' needs and refer to appropriate providers/specialists for both in and out of network benefits, including mental health, drug and alcohol use, treatment adherence, and family planning.

### ***To promote care coordination and successful implementation of the SNP case management benefit:***

- Clarify the function of case management and the ways in which a consumer can best navigate the benefit.
- Provide data to the HIV/AIDS community that indicates whether coordination of covered and non-covered services is occurring.
- Offer clear explanations to community-based organizations on how each individual SNP case management system works, how SNP case management coordinates with COBRA case management, and what the benefits are of having both COBRA and SNP case management.
- Produce data on whether assessments of medical or psychosocial needs are appropriately relayed by the case manager to all parties involved in a member's health care.
- Educate medical providers about the distinct roles of COBRA and SNP case management.

### ***To ensure quality care in SNPs:***

- Make available all IPRO, HIV QARR, and dynamics of care study data as soon as it is collected.
- Publish data on number of complaints, internal and external appeals, and outcomes.
- Conduct quarterly patient satisfaction surveys and make available for public review.
- Consider contracting with community-based organizations as neutral third parties to collect data and conduct client surveys.
- Publish comparison data on SNPs, mainstream managed care, and fee-for-service Medicaid.

# Introduction

## *Medicaid Managed Care for People with HIV/AIDS*

For years managed care has been used as an alternative to fee-for-service health care delivery. In managed care, providers are paid a predetermined amount for each person they treat, and consumers visit only those providers who participate in their plans' networks. As health care costs have risen many times the rate of inflation over the last several years, states faced with growing Medicaid budgets have implemented managed care in their Medicaid programs in an effort to rein in costs.

In 1991, New York State began the transition to Medicaid managed care with the passage of the Medicaid Managed Care Act, which created a voluntary managed care program for people in Medicaid. In 1995, the State applied for and was granted a Federal 1115 waiver that allowed the State to make the managed care program mandatory for almost all enrollees. Due to vigorous advocacy by HIV/AIDS and other health care advocates, "special populations," including people living with HIV/AIDS, were exempt from making the transition to mainstream managed care. The health care and social needs of people with HIV/AIDS (as well as other groups, including SSI beneficiaries, persons with mental illness and Medicare enrollees) were perceived as too complex to force a transition to a one-size-fits-all managed care model. As part of the waiver, however, the State began designing a Medicaid managed care model specifically to meet the needs of people living with HIV/AIDS.

HIV Special Needs Plans (SNPs) were developed to achieve two goals in the delivery of health care to HIV-positive Medicaid beneficiaries in New York: contain expenditures for a high-cost population and coordinate care for people with HIV/AIDS to reduce disease progression. SNPs were based on the model of Medicaid managed care (network of providers, capitated provider payments, emphasis on preventive care and education) and augmented with enhanced services for people with HIV/AIDS such as treatment adherence services and education, case management, alcohol and drug treatment, and HIV specialists as primary care physicians (PCP). In a unique collaboration, state and local administrators, community-based organizations and advocates, providers, and policy makers were involved in the development of the SNP model and in the creation of SNP-specific capitation rates. While the model was in development, researchers from Memorial Sloan-Kettering Cancer Center designed a study to monitor client experiences of the shift from fee-for-service Medicaid to SNPs. After years of development, five SNPs began voluntarily enrolling people living with HIV/AIDS on Medicaid and their children in the spring of 2003. Given all the efforts that went into making SNPs an inclusive model and responsive to the unique needs of HIV-positive Medicaid beneficiaries, feedback on the first two years of SNP operation is important.

## *SNP Facts*

HIV Special Needs Plans are voluntary; HIV-positive Medicaid beneficiaries can choose whether or not to enroll based on their own needs and preferences. If they do not enroll in a SNP, they can remain in fee-for-service Medicaid (sometimes referred to as “regular” Medicaid) or can join a mainstream Medicaid managed care health plan.

SNPs operate in New York City only, and there are currently five SNPs in operation: Fidelis HealthierLife (operating in all five boroughs), HealthFirst (operating in all boroughs except Staten Island), MetroPlus Partnership in Care (operating in all boroughs except Staten Island), New York Presbyterian Healthcare System SelectHealth (operating in all boroughs except Staten Island and Queens), and Vidacare (operating in Bronx and Manhattan; expanding to Brooklyn). Community Care Partners, a sixth SNP, is expected to begin enrollment soon. The five operating SNPs began enrolling members in the summer of 2003. As of March 2005 there were a total of 1,283 SNP enrollees citywide (see Table 1)<sup>1</sup>, representing a small fraction of the HIV population in Medicaid eligible for SNP enrollment.

*(Note: As of the time of the printing of this report, Fidelis HealthierLife and Health First have stopped participating in the SNP program.)*

**Table 1. Cumulative SNP Enrollment from Implementation to March 2005**

Month	Cumulative Enrollment
July 2003	41
August	103
September	152
October	237
November	317
December	364
January 2004	399
February	453
March	526
April	625
May	708
June	746
July	859
August	934
September	996
October	1013
November	1065
December	1088
January 2005	1165
February	1226
March	1283

## *SNP Success*

HIV SNPs mark a dramatic change in the way HIV care is delivered in New York State and in the United States. HIV-positive Medicaid beneficiaries are at the center of a new system of care delivery that will not only have an impact on their health, but will serve as a test pilot for the development of other models of health care for populations with chronic diseases, disabilities, or complex health care and social needs in New York and across the country. First and foremost, advocates and consumers alike want SNPs to succeed. A new model of health care designed

specifically with the needs of HIV-positive consumers in mind, and the resulting partnership between government and the community to discuss SNPs’ strengths and weaknesses, is a positive step in the evolving world of health care delivery. However, there is so much uncertainty in the lives of people with HIV/AIDS, from monitoring T-cell counts, to following complex drug regimens, to dealing with the stigma and difficulties of living with the disease, that SNPs must meet expectations for high quality care, and include failsafe mechanisms to ensure no

individual with HIV/AIDS falls through the health coverage cracks. Government representatives, providers, and advocates also want to ensure SNP success so that there is a strong foundation on which to build the SNP program if or when SNPs become mandatory. Without a doubt, a transition to mandatory SNP enrollment will have a profound impact on the lives of people living with HIV/AIDS.

This report is a snapshot of how the SNPs are faring at this point in time. The paper proposes a framework to assess whether or not the SNPs are meeting the goal of providing quality care to people living with HIV/AIDS. SNPs must succeed on a smaller scale, and in the context of voluntary enrollment, before any attempts are made to implement mandatory enrollment for the 65,000 HIV-positive

Medicaid beneficiaries in New York State. Also, because the per-capita payment to SNPs is significantly higher than mainstream managed care, there is an even greater need to ensure that services are provided—the city and state as purchasers of health care should be aware of whether they are getting value for the dollar. While the following indicators will highlight some of the key policy variables that should be measured to evaluate SNP success, the personal stories of the people enrolled in SNPs are valuable examples of how the plans are working, or not, for people living with HIV/AIDS. Included in this report are five consumer experiences that, while not necessarily representative of all SNP enrollees, highlight some of the benefits and drawbacks of enrolling in SNPs.

### *SNP Implementation Issues*

As SNPs become fully integrated into New York's system of managed care and increasingly become an alternative to fee-for-service Medicaid for people living with HIV/AIDS, it is important to determine whether the plans are meeting benchmarks set forth in the SNP model contract<sup>2</sup>. The contract enumerates requirements and standards that the plans must meet, such as coverage of benefits, timelines by which enrollees have to be

contacted, standards for case management, and rules and regulations regarding SNP marketing. The SNP model contract provided the framework for the following “tests for success”: issues that are important to a successful voluntary SNP program. Based on the contract, these “tests” represent the most important elements of a successful managed health care plan for people living with HIV/AIDS.

# “Tests for Success”

## *Outreach and education*

For people contemplating whether or not to change the way they access health care, first impressions about a SNP are very important: the experience of talking to an enrollment representative or getting a flyer in the mail about a health plan can leave lasting impressions on the consumer. Understanding the complexities of health care plans, determining whether one's providers are part of a health plan network, and making decisions that impact one's family members are difficult factors to weigh when deciding whether to join a SNP. Getting information to help make these decisions is critical for the consumer. It is also key in measuring the success of voluntary implementation, since it is likely only those who are educated about SNPs will choose to enroll.

The most fundamentally important factors that will determine the program's success in enrolling new members are whether New York State and the SNPs are getting the word out that they are available, and how clearly and accurately they describe what they have to offer people with HIV on Medicaid. If Medicaid consumers have never heard of SNPs, or do not have a clear picture of what they are and how they may be preferable to fee-for-service Medicaid or mainstream managed care, then SNP enrollment will grow slowly and the program will not “brand” itself in the HIV community.

Reaching out to potential enrollees and making the case for SNP enrollment is an important first step to a successful program. Once a SNP has a potential enrollee's attention, that person must be educated about SNPs and made aware of the differences and similarities between SNPs and regular Medicaid, such as benefits, choice of providers, utilization of networks of care, eligibility of both positive and negative family members, newborn enrollment, and grievance procedures. Education is especially

important given that enrollees may not speak English as a primary language or may have disabilities or impairments that can make understanding SNPs even more difficult. Only an individual who is fully knowledgeable about the SNP under consideration will be satisfied by his or her decision to change their system of care.

It is also critical that providers have accurate information about what SNPs are and how they function, since consumers may turn to their medical or community-based provider for information about a SNP. Since SNPs seek out providers in efforts to expand their networks, providers can be sources of information for people who are considering enrolling in a SNP and may hold considerable sway over a consumer's decision whether or not to join.

Since SNPs' inception, New York State, New York City, and the plans themselves have distributed materials and utilized the media to increase awareness of the SNP option in Medicaid. These materials and campaigns include:

- General SNP advertisements in subway stations, trains, and on billboards near groceries/bodegas
- Consumer SNP brochures in new Medicaid enrollees' packages (available in English, Spanish, Russian, Chinese and Haitian-Creole)
- Presentations by New York Medicaid Choice (Maximus) to community-based organizations/case managers and providers
- Presence of Maximus enrollers in HIV/AIDS Services Administration (HASA) locales
- SNP direct-to-consumer marketing in magazines, papers and television
- Public service radio announcements in English and Spanish

- Laminated fact sheets mailed out to community-based organizations
- Series of trainings and distribution of “Making the Right Choice” publication for case managers so that they may help consumers decide if SNPs are right for them
- SNP community health fairs
- SNP videos and webcasts for consumers and providers
- Series of trainings for Ryan White networks on SNPs and distribution of case managers tool kits
- Presentations by AIDS Institute executive staff to provider and consumer groups, the Ryan White networks and government agencies

SNPs have had difficulty reaching people who may be eligible because confidentiality laws and the stigma associated with HIV prevent a direct, targeted way to appeal to people about the plans. For example, New York State cannot identify HIV-positive Medicaid beneficiaries based on HIV status, pull their names and addresses, and send a mailing on SNPs. Additionally, a SNP would find it difficult to attract consumers at a public street fair since people approaching the SNP would be presumed to be HIV positive. Limited resources also present a problem: Thus far, SNPs have been unable to wage an aggressive advertising and outreach campaign since

resources have been dedicated largely to consumer care, improving provider networks, and strengthening internal operations. At community forums hosted by GMHC, SNP representatives have expressed concern that too few consumers are hearing about the SNPs and indicated that the State, community-based organizations, and providers together need to be more involved in SNP outreach efforts.

Despite the challenges to achieving widespread SNP education, those who choose to enroll in SNPs do report that they understand basic concepts of the plans. According to a survey conducted by Memorial Sloan-Kettering Cancer Center, data show that consumers received critical information that helped them make an informed decision about joining a SNP. In a survey of 200 SNP enrollees in June 2004<sup>3</sup>, enrollees reported they were told the following:

<b>SNPs are voluntary</b>	<b>80%</b>
<b>They have a choice of plans</b>	<b>72%</b>
<b>They can disenroll any time</b>	<b>84%</b>
<b>They are required to use SNP network</b>	<b>82%</b>
<b>They can use ER for emergency</b>	<b>86%</b>
<b>They need Medicaid card for some services</b>	<b>87%</b>

These stories highlight some of the real life experiences of people enrolled, or thinking of enrolling, in HIV Special Needs Plans. While these are just a small sample of experiences and do not reflect the opinions and thoughts of SNP consumers on the whole, they nevertheless provide insight and reflections on what it is like to be in a SNP and what some of the potential benefits and drawbacks may be.

Names of individuals interviewed for this project were changed to protect anonymity.

## Bruce’s Story

*Bruce is 53 and lives in Queens. Before he moved to the U.S. in 1995, he was a teacher. Right now he is worried about “trying to survive” with HIV. He has a low T-cell count, high viral load, and is worried about making sure he has the medications he needs.*

*HIV has made a huge difference in his life — “it determines everything.” He tries to stay healthy by following the instructions of his physicians, and leads a cautious life.*

While there is room for improvement, these statistics are positive indicators that enrollees are getting important information about SNPs. It seems the challenge is to continue educating the broader HIV/AIDS community about SNPs and to explain how they may be preferable to regular Medicaid. Based on conversations with HIV/AIDS advocates and frontline workers, and on the data showing the slow enrollment rate of SNPs, it seems that not everyone is clear about what SNPs are and what benefits they have to offer beyond traditional managed care.

SNPs continue to face a challenge as to how they will conduct outreach and education efforts to reach those beneficiaries not connected to their current networks. Several of the SNPs have natural constituencies from which to draw. For example, one of the SNPs is run by several day treatment centers that work daily with and for consumers. Other SNPs are run by health plans and hospitals that similarly have a clientele that is already connected to their Medicaid system. However, once these plans have enrolled people they see regularly, they will need to reach a broader, unconnected population of HIV-positive Medicaid beneficiaries who may have no concept of SNPs and what they offer, or who rarely access Medicaid.

Effective marketing, outreach, and education strategies are critical for voluntary health plans. Due to budgetary

reasons, the state has not been able to send a SNP brochure to all Medicaid enrollees. The State Department of Health subway SNP poster campaign has ended, so it has been largely up to the plans themselves to advertise in the public realm. Some community-based organizations educate their clients about SNPs, but many organizations are still unsure about how SNPs work and why they may be more appealing to a potential enrollee. More financial resources are needed to advertise SNPs and make them more visible in the AIDS community.

Health fairs in which SNPs are able to talk to clients one-on-one about their plans and services are an effective way to inform people and answer specific questions about their plans. Health forums at HIV/AIDS community-based organizations or at places where people with HIV/AIDS gather would be an effective way for the SNPs to market their plans without the fear of stigma attached to a location at which people with HIV/AIDS could be singled out. SNP fairs provide a good format to engage clients one-on-one and educate potential enrollees about what SNPs are and how to get enrolled. Having provider directories on hand can ensure enrollees that the SNP they join will allow them to see their current physician if they prefer, and which other physicians in their area they may be able to see in the network.

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*To keep healthy, he does not smoke, does not drink, and does not do drugs. He tries to get the right food and medication to keep him feeling good. He sees a dentist and an eye doctor.*

*Bruce heard about SNPs for the first time when he got a letter in the mail from a community-based organization about the SNPs. Before the letter, he had never heard of them. No one has approached him about joining a SNP.*

*In order to decide whether or not he would want to join a SNP, Bruce says he would “need information as to whether the program will be better than what I am receiving right now [regular Medicaid].” In deciding whether or not to join a SNP, Bruce says, “I’m not sure I want to change providers at a time when I’m trying to stay alive and live a little bit longer, and survive a little bit. I have a very good doctor.”*

## Enrollment

The ease or confusion of enrolling in a SNP has implications for both the individual joining the SNP and the success of the program on the whole. Enrollment is often the first meaningful contact between consumers and plan representatives. Negative enrollment experiences may leave a consumer with doubts about his/her decision to join a SNP and may lead to confusion and an interruption in care, while positive experiences may make the consumer pleased with his/her decision to join a SNP and encourage others to join who may be contemplating the same. SNP enrollment can occur in several ways: at the point of Medicaid enrollment; by contacting New York Medicaid Choice (Maximus) or seeing a Medicaid Choice field enrollment counselor; or by enrolling with a SNP marketing representative (or contacting a SNP directly to get enrollment information). Detailed and accurate information is critical at this point, as consumers likely have numerous questions that need answering before they will join.

According to the New York State AIDS Institute, an enrollment survey of 200 SNP participants in June 2004<sup>4</sup> showed that:

Percent of those responding who felt “completely” or “mostly” satisfied that:	
They received the information needed about how the plan works	79%
Their confidentiality was maintained	90%
Their questions were answered	84%
They had time necessary to get information and get enrolled	88%

This data is positive. More information needs to be collected, however, to flesh out the results suggested in this study. For example, there is no way to gauge from this information whether the 84% of enrollees who received answers to their questions got the right answers. With the health of vulnerable consumers at stake it cannot be overstated how essential it is for consumers to receive accurate information prior to and following enrollment in a SNP. Therefore more data must be gathered to tease out the positive and negative experiences encountered during enrollment in order to improve and streamline the process.

It is likewise important to determine whether plan selection is happening at the point of enrollment, how people go about choosing plans, whether they have sufficient information to choose a plan, and/or whether they are enrolling in a plan erroneously, and subsequently disenrolling. Since the onus rests on the consumer to choose a plan wisely, plan selection is a critically important step in the enrollment process and should be monitored closely.

## Sean's Story

*While he was waiting for care one day, Sean was approached by an on-site SNP enroller who said “you qualify for SNPs” and that most people will be in a SNP eventually and “we don’t know when, but at some point everyone will be in a SNP.”*

*Not understanding that SNPs were not mandatory, Sean asked “how much time do I have to get into the program?” The enroller replied “I don’t know — 6 months, 8 months, 1 to 2 years, but eventually everyone will be put into*

## Continuous care

Continuity of care is the ability of a new enrollee to maintain access to health services and medications and/or avoid interrupting care relationships that could have a negative impact on his or her health. It is a critical factor during the early stages of an individual's SNP enrollment. Interruptions in treatment regimens for people living with HIV/AIDS can cause medications to lose effectiveness and regimens to fail. Part of measuring the success of SNP implementation is determining whether the shift from one type of Medicaid to another is as smooth as possible to ensure no harm is done to the enrollee. As advocates witnessed in the transition of non-exempt enrollees in fee-for-service Medicaid to managed care in the late 1990s and early 2000s, this transition is not always seamless, and consumers certainly run the risk of losing access to their health care entirely if they are not transitioned properly.

Once someone chooses to enroll in a SNP, enrollment is verified by mail, usually the first day of the month following the individual's application. The new enrollee is sent a member handbook outlining covered benefits, how to access services, important contact information, and instructions on how to dispute a coverage decision or disenroll from the plan. They are also sent a list of participating providers in the SNP network. For newborns, enrollment occurs the day the SNP receives notification of the birth.

Beyond the basic services that Medicaid offers, SNPs offer an enhanced set of benefits that are specifically tailored to people living with HIV/AIDS including:

case management, treatment adherence services, HIV prevention, and risk reduction education. Mental health and substance use treatment are also covered by SNPs, and enrollees can still get access to other Medicaid benefits including dental, adult day health care, COBRA case management, and hospice. One of the most important features of the SNP is the assignment of an HIV specialist as a primary care provider. An enrollee can choose a primary care physician at the time of enrollment, but if he or she does not, one is assigned within 30 days of the effective date of enrollment. All of these benefits and services need to be readily accessible once a beneficiary has joined the SNP.

There are several responsibilities SNPs have in ensuring continuous care for new enrollees. The HIV/AIDS community can determine whether the SNPs are fulfilling their contractual obligations to their members by analyzing data on whether these are met within the specified time frame.

Questions derived from the SNP model contract that can help determine whether continuity of care is ensured in a SNP include:

- How long does it take to assign a primary care physician to the enrollee?
- Are the enrollees provided with a service plan within 30 days of enrollment?
- Do enrollees with "ongoing needs" get to see their primary care physician within the first 7 days of enrollment?  
If they need urgent care, can an appointment be made within 24 hours?

*the program, and I will be bombarded with clients getting into the program, and there will be a waiting list since there will be so many applications. So enroll now so you don't have to be on a waiting list."*

*The enroller did say that there were other SNPs available to enroll in beside hers, and that the SNPs were "getting good reviews because people are called and there is follow-up." He told the enroller "I'll make a decision the next time I come here for an appointment." Sean said, "I had a bad taste and a bad feeling from that conversation. It leaves me with a lot of doubt and with a sense that I have no choice."*

- Can the enrollee continue to see a non-network provider for 60 days post-enrollment if necessary (e.g., in cases where an enrollee is pregnant, or is seriously ill, or their provider leaves the SNP network)?
- Do the plans contact the enrollees within 15 days of enrollment? What are the findings from the “non contact” reports (the reports indicating who cannot be reached by the plan)?
- How many people are changing their primary care provider within the first 90 days? Why?
- Have enrollees been able to access care within specified time frames?

Because of low SNP enrollment, there is only a limited amount of data to indicate whether enrollees are receiving uninterrupted care. Data from an August 2004 survey<sup>5</sup> showed that on average SNPs:

<b>Provided new enrollee orientation within 15 days</b>	<b>81%</b>
<b>Could not reach enrollee within 15 days or after 6 attempts including home visits</b>	<b>5%</b>
<b>Assigned adult PCP within 30 days</b>	<b>100%</b>
<b>Assigned Child PCP</b>	<b>100%</b>
<b>Assigned case manager</b>	<b>100%</b>
<b>Verified HIV status</b>	<b>99%</b>
<b>Verified AIDS status</b>	<b>99%</b>

These data indicate a great deal of success ensuring enrollees are linked to care upon enrollment; however, the sample is small. There is no additional data available to indicate whether members are able to access other benefits, including mental health, treatment adherence, family planning, substance use counseling, etc. However, these data are very promising indicators that the trigger actions that should occur once a person is enrolled in a SNP are indeed occurring.

More data is needed to determine whether enrollees are getting referrals when needed, whether carved out services are being accessed in a timely manner, how often communication occurs with the SNP after the first month of enrollment, and why enrollees choose to disenroll or switch primary care physicians. More data should be compiled and shared with the broader HIV/AIDS community for a more comprehensive, accurate analysis.

## Kenny's Story

*Kenny lives in Harlem, is 57 years old, and uses Medicaid. The most important aspect of care for Kenny is his doctor—“My doctor and I have such a rapport that we don’t only talk about my medical life, but about my real life.” He feels his doctor knows him well, and puts their relationship like this: “My doctor is like a cabbie, and I am directing him where to go.”*

*Kenny is currently enrolled in a SNP and says it’s “great.” He found out about the SNP when his doctor told him about it 2 years ago. At first, he says, he*

## Case management and care coordination

Many people who are HIV positive have other life situations that complicate their health care, including limited financial resources, mental health issues, drug use, homelessness, and other medical ailments that may or may not be associated with HIV. For this reason, one of the goals in the development of the SNP model was to offer a program that would coordinate care for HIV-positive Medicaid beneficiaries in an effort to achieve better health outcomes. Care coordination tries to ensure that all the different people who are involved in a patient's care—his or her physicians, advocates, and other providers, such as nutritionists, pharmacists, and counselors—are aware of what the others are doing for the individual. With coordination, a beneficiary's health status can improve and care delivery can be achieved more efficiently.

Case management is a unique and important component of an enrollee's care coordination. Case management is a tool used to coordinate an enrollee's medical care and other services that may impact their health and well-being, such as referrals for social services, including counseling and drug treatment, legal assistance, making medical appointments, navigation through bureaucratic entitlement programs, and assistance organizing their family members' needs. The SNP case management benefit includes medical and psychosocial case management. Studies have shown that case management is cost effective, can increase access to health care, and encourage people to remain in care, especially those with an AIDS diagnosis.<sup>6</sup>

Case management as a concept is defined by New York State as:

An approach to service delivery which strives to ensure that clients with complex needs receive timely coordinated services and that resources are utilized in order to maintain an individual's ability to function independently in a community of their choice as long as practical...in addition to the primary role of service coordination, case managers also assume a variety of roles which are complementary to coordination.<sup>7</sup>

There are two primary types of case management covered by Medicaid SNPs—SNP case management and COBRA case management.

### **SNP case management provides:**

- Clinical coordination and medical/clinical case management in consultation with the enrollee's primary care physician
- Service utilization monitoring
- Assessment and service plan development that address identified medical needs
- Case manager involvement in quality assurance and quality improvement
- Non-intensive psychosocial case management including: psychosocial and supportive services coordination; comprehensive assessments and 180-day reassessments; and management of basic entitlement and advocacy issues that may extend beyond clinical coordination and the medical case management role.<sup>8</sup>

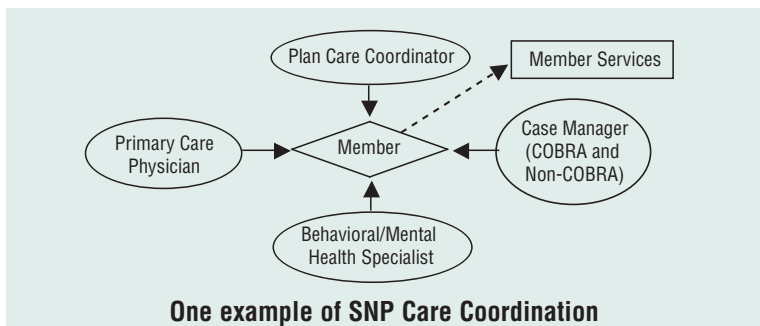
*was not interested. As he heard more about it, he found out his doctor was part of the SNP. Kenny likes his SNP because the members have a say in the way the plan is structured, which is "long overdue" in healthcare.*

*He says he also likes his SNP because they "know you — you know who the people are who you're dealing with and who are helping you. You know them, and they know you. Most people at [my SNP] can identify you, and they are your neighbors. When you see the faces of people you are talking to, that makes a difference."*

### COBRA case management provides:

- Coordination of services for people who face enormous barriers to care, such as poverty, drug and alcohol use, homelessness, domestic violence, and lack of support of care and access to care. This is also called intensive case management and is paid for directly by Medicaid. In addition to a SNP case manager, enrollees can still utilize COBRA case management either in the SNP or through non-SNP providers (like community-based organizations), as this is a carved-out Medicaid benefit.

Care coordination and case management can vary by SNP. If a SNP chooses to separate these functions, the care coordinator (also known as a medical case manager or a nursing care coordinator) ensures that an enrollee's care is managed, i.e., making certain the primary care provider, the case



**One example of SNP Care Coordination**

manager, and, if applicable, the mental health care provider are knowledgeable about one another's work on behalf of the enrollee. Non-intensive psychosocial case management can be provided by the SNPs themselves, but is more likely to be provided by community-based organizations that have contracts or linkages with SNPs to provide these services. COBRA case management can be accessed by a SNP enrollee since it is carved-out of the SNP benefit package and available through fee-for-service Medicaid.

SNP case managers must work with an enrollee's primary care physician to coordinate medical care, develop a care plan for the enrollee, and arrange social and other medical services for the enrollee, including treatment adherence, drug treatment, domestic violence help, and risk reduction education. Case managers should assist enrollees with navigating the system of managed care, including directing enrollees to in-network and where appropriate out-of-network providers, and helping enrollees access carved-out services. Case managers must be assigned to enrollees within 30 days of enrollment, and must assess them at least once every 180 days.

The inclusion of case management in the SNP benefit package raises questions such as:

- How have the Medicaid entitlement, the clinical needs, and the psychosocial needs of a member been integrated?
- How has a case manager monitored the coordination for both covered and non-covered services?
- How has the case manager assured quality of care?
- Did the State Department of Health review SNP-community-based organizations linkage agreements and what was found?
- How have special needs been identified by SNP and appropriate referrals made (e.g., a consumer who has a developmental disability is referred to whom? How?)
- How does HIV and non-HIV related information flow between the SNP case manager and a member's COBRA case manager?

## Jose's Story

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*Jose is enrolled in a SNP. He receives calls at home but does not welcome them and thinks they are unhelpful. He says, "Once, when I told the person who called me about my issue with the specialists in my plan, he told me to call a phone number. Why couldn't he help me? He was with the SNP, right? I*

- What education has been given to medical providers about the distinct roles of COBRA and SNP case management?
- How do SNP case managers deal successfully with non-HIV medical issues such as Medicaid recertification, foster care, homelessness, etc?

There is no data available yet that show how members' needs have been assessed, how referrals are made to appropriate providers, or whether SNP case management is coordinating smoothly with a member's COBRA case management. There is also no quality measurement data to determine whether coordination among benefits is occurring.

SNPs are able to structure their case management benefits differently from one another, so analyzing the quality of case management should be done on a plan by plan basis. The fact that some people need a lot of case management in their lives and some need little assistance should also be taken into consideration when assessing SNP success in case management. It is still unclear how a SNP case manager and a community-based organization case manager for the same person will communicate with one another when their duties overlap, and whether one type of case management will take priority.

Data should be collected to determine whether SNP case managers have appropriate decision-making authority within each SNP: case managers need to be navigators so they can help people through the system, and not merely utilization review and control staff used to limit services or referrals. Case managers should also be surveyed to determine whether they believe they are effective in

coordinating care. Consumer satisfaction surveys are also needed to determine if enrollees find care coordination useful, and clinical indicators of poor care coordination should be identified and monitored.

New York State should also determine whether the overlap of SNP case management and COBRA case management is cost-effective. COBRA case management mandates that case managers obtain information on medical assessments and treatment adherence, similar to the responsibilities of SNP case managers. Data collection seems to overlap, raising the question of whether this is an efficient use of Medicaid dollars. While clients report that they use COBRA case management because it is usually based in the community and it provides social support, SNP case management may be more conducive to coordinating an enrollee's medical needs. The relationship between the two models of case management needs to be clarified for enrollees, providers, and community-based case managers alike, as exactly how case management works in the context of all the factors at play in SNPs is still not entirely clear.

The case management benefit in SNPs provides a unique opportunity for the HIV community to have a more formal role in the medical care of HIV-positive clients, as SNPs allow for the marriage of clinical and community based providers through the care coordination benefit. The State acknowledges that case management in SNPs is still evolving, and with more experience, case management will not be an end in itself, but the means to providing a beneficiary with care coordination and care advocacy.

*expected him to have a better answer. All the caller did was ask me some questions, and said that's all he called for. They don't suggest anything, and they leave it up to you to figure out. So now, I don't want to talk to them. When they call to ask me if everything is fine, I say it is, but really it's not."*

## *Accountability for high quality care*

Ultimately, the most important test of the SNP program is whether people are getting the care they need when they need it. Quality measurements must ensure that care is delivered effectively, in a time efficient manner, and is appropriate to the needs of the individual.

Every year, managed care plans in New York must submit performance data to the New York State Department of Health Office of Managed Care. These data are collectively known as the Quality Assurance Reporting Requirements (QARR)<sup>9</sup>. Per the model contract, each SNP must operate an internal quality assurance program, establish a quality assurance committee, develop a quality assurance plan, and meet quarterly. Procedures for quality assurance must measure compliance with performance standards of the State Department of Health: appropriateness, accessibility, timeliness and quality of care delivered, access to specialty services, referrals oversight, and cultural and linguistic appropriateness of care.<sup>10</sup>

In addition, HIV-specific QARR measures have been established to evaluate the SNP providers and determine whether they are meeting the needs of HIV/AIDS population for which they were designed. The initial HIV QARR analysis will include measures for ARV management, adherence to antiretroviral therapy, and HIV monitoring. Over the next several years additional measures will be incorporated into the survey. These will include: cervical cancer, chlamydia, syphilis, gonorrhea, PPD (tuberculosis), and adult mental health screenings, chemical dependence assessments, childhood

immunizations, MAC and PCP prophylaxis (preventing opportunistic infections), pelvic exams, lipid screenings, baseline assessment initiations, and complete medical evaluations.

Currently there is no QARR data for the SNPs because the program does not have enough people who have been enrolled for six months or more to have a statistically sound cohort from which to collect data. Similarly, there is no HIV-specific QARR data. As more people enroll in SNPs, data will be collected and should become useful to advocates and policymakers to determine whether SNPs are indeed providing quality health care. In addition to QARR data, the Memorial Sloan-Kettering Cancer Center study is collecting data on SNP consumer satisfaction, and measuring outcomes on treatment adherence, preventive health and screening, substance use, and life circumstances and demands. These data should be made available to the public quarterly.

Quality measurements are critical indicators of SNP success; the State must be able to hold the plans accountable to ensure quality care within each plan. The movement of people with HIV/AIDS into managed care is a significant change in the delivery and financing of HIV care, and these measures are the only way we can ensure that SNPs are indeed offering enrollees appropriate and timely care that is equal to or better than what is offered through the traditional Medicaid program. As such, the following issues, in addition to QARR data, should be measured and reported to the public as soon as possible, especially if mandatory enrollment is proposed:

## *Al's Story*

*Al lives in the Bronx and is 54 years old. He is single and is a design professional. He says he is "not a victim" and does not let HIV control his life. Al says, "I am enrolled in [a] SNP and I love the people who help me with my benefits and my health needs. My doctor is instrumental in making sure my regimen is the correct combination of drugs, and helps me with my stress*

- *Data indicating whether the member services hotlines give enrollees and potential enrollees the information they need in order to make informed decisions about the SNPs.* Member services departments are supposed to explain how to access services, assist in picking or changing a PCP, help make appointments with providers, and answer questions about complaints, appeals, and fair hearings.
- *Access to carved-out services, and whether enrollees are using the right card to access them, including prescription drugs, adult day care, and hospice.* There should also be data on whether there is difference in access for enrollees who receive reproductive care through their health plan and those who must access it outside of their SNP.
- *Data on cultural and linguistic competency of the SNPs.* Data should indicate whether people who do not speak English as a first language are/are not able to communicate with their member service lines, providers, case managers, etc. Mainstream Medicaid managed care has had problems ensuring that people with Medicaid are able to get all the interpretation services they need; SNPs need to measure this as well. Providers should be able to speak the language of the patient, or be able to communicate via an interpretation device. Written materials must be available in other languages if the people who speak the language constitute a significant community within a certain geographic area.
- *Data on SNP disenrollment, including reasons that the member disenrolled or was disenrolled from the plan and where they were reenrolled (another SNP or fee-for-service Medicaid).* According to the New York State Department of Health's Quarterly report for the Section 1115 Partnership Plan Program covering July 1 to September 30, 2004, a total of 16 people disenrolled from the SNPs. From SNP inception, approximately 245 people have disenrolled. Consumer feedback on why individuals chose to disenroll should be collected, made public, and used to improve SNP operations.
- *Access to data on complaints, internal and external appeals, and determinations.* Enrollees should be getting written notice about negative coverage decisions made by their plan. According to the SNP model contract, enrollees can file for an appeal if their complaint is turned down or file for an external review if it is a decision based upon a utilization review, or request a fair hearing. We should see data on decisions made in the plan's favor and those made in the beneficiary's favor, and on whether the decisions are made within the appropriate timeframe as indicated in the model contract.

*management.” Last year Al was diagnosed with prostate cancer, and he had “amazing” care through his SNP. He says “the best thing about his SNP is that it’s convenient: I don’t have to go to several different doctors — everything is coordinated and confidential information about my health care is shared only with people who are supposed to see it in my network. If a medical problem comes up, I call my doctor and I usually get through to him quite easily.”*

# Recommendations

SNPs represent a new model of health care designed specifically to meet the needs of HIV-positive Medicaid beneficiaries. It is in the best interests of consumers, advocates, providers and government representatives alike for SNPs to be successful. Therefore we recommend the following to strengthen the SNP program for current and future enrollees. Enrollment should not become mandatory until these recommendations are achieved.

## *To increase public awareness of SNPs:*

- Increase state and city funding for SNP consumer education and production of SNP advertising materials.
- Utilize new, culturally diverse avenues to promote SNPs, including SNP health fairs at locations where people with HIV/AIDS congregate, and mailings to all current Medicaid beneficiaries.
- Work directly with community-based organizations to increase front line worker knowledge of SNPs.
- Emphasize the difference between SNPs and mainstream managed care, and highlight the enhanced benefits in the SNP model.
- Ensure consumers understand that SNPs are voluntary, and they have a choice of whether or not to enroll. Potential enrollees should always be told that they have a choice of plans.

## *To ensure continuous care:*

- Collect and publish data on whether or not SNPs are meeting their contractual obligations to: enroll people in timely way; assign a primary care provider and case manager within 30 days; ensure enrollees are receiving continuous care;
- and assess enrollees' needs and refer to appropriate providers/specialists for both in and out of network benefits, including mental health, drug and alcohol use, treatment adherence, and family planning.

## *To promote care coordination and successful implementation of the SNP case management benefit:*

- Clarify the function of case management and the ways in which a consumer can best navigate the benefit.
- Provide data to the HIV/AIDS community that indicates whether coordination of covered and non-covered services is occurring.
- Offer clear explanations to community-based organizations on how each individual SNP case management system works, how SNP case management coordinates with COBRA case management, and what the benefits are of having both COBRA and SNP case management.
- Produce data on whether assessments of medical or psychosocial needs are appropriately relayed by the case manager to all parties involved in a member's health care.
- Educate medical providers about the distinct roles of COBRA and SNP case management.

## *To ensure quality care in SNPs:*

- Make available all IPRO, HIV QARR, and dynamics of care study data as soon as it is collected.
- Conduct quarterly patient satisfaction surveys and make available for public review.
- Publish comparison data on SNPs, mainstream managed care and fee-for-service Medicaid.
- Publish data on number of complaints, internal and external appeals, and outcomes.
- Consider contracting with community-based organizations as neutral third parties to collect data and conduct client surveys.

HIV Special Needs Plans mark the arrival of a new delivery system of health care for people with HIV on Medicaid. The movement of people from the traditional Medicaid program into SNPs will have ramifications for both enrollees and the entire Medicaid system. People with HIV are a high cost population in Medicaid, and as more people enroll in SNPs, the system must respond to the particular needs of people living with HIV, including the importance of treatment adherence, the changing nature of their disease, and other factors that often complicate one's HIV status, such as multiple health conditions, and financial and social factors.

For these reasons, SNP success is extremely important. It is important to the people enrolled; it is important to the HIV community in understanding there is another health care option in Medicaid; and it is important to health policy experts who are trying to devise new ways of providing care for people with chronic illnesses like HIV. SNPs also have to find a way to convince people that they are not just managed care, but rather are unique new models of care tailored to people with HIV that offer more than a traditional managed care plan. To get away from the commonly held belief that "managed care is bad," SNPs need to do a better job of defining themselves in the community, distinguishing themselves from managed care, and integrating advocate and consumer input into the model.

# Conclusion

There are broader health care issues currently in play that may affect SNPs. Reforms to Medicaid at the federal and state levels may dramatically alter the landscape in which people with HIV access Medicaid. In 2005, many proposals, if implemented, will likely limit the benefits and services that people receive on Medicaid. A change in the entitlement nature of Medicaid, such as a cap on federal matching funds, would likely restrict New York's program. HIV SNPs may be an alternative that provides people with HIV an enhanced benefit package and mandated services, like access to specialists, that may be limited in the traditional Medicaid program in years to come. Attempts to "medicalize" the Ryan White Care Act and limit supportive services offered through the program may make SNPs a unique and desirable alternative for beneficiaries.

Despite the potential that SNPs have, the plans should not become mandatory until the tests outlined in this report have been passed. While the state and/or the plans may desire a mandatory program to increase enrollment and provide predictable costs associated with HIV care in Medicaid, it is unwise to force a medically vulnerable population into a system of care that has yet to be thoroughly scrutinized. Provider capacity, enrollment protocol, coordination of benefits, and details of SNPs' plans to reach out to people who are beyond their traditional scope of network are still factors that need more study. The slow start of the SNPs has afforded the State, the SNPs themselves, and the community an opportunity to understand the pros and cons of HIV SNPs. Until they are proven to provide comprehensive, reliable care and are user-friendly, the SNPs should remain a choice, and not a mandatory program. People with HIV need to have a backup in regular Medicaid if a SNP is not the right fit for them.

As important as the SNP "tests for success" are, the experiences of the people enrolling in SNPs are an equally critical barometer. All SNPs stakeholders need to regularly talk to enrollees to judge whether or not the SNPs are meeting member needs, and to identify the program's strengths and weaknesses in order to better inform the SNPs as they enroll more and more New Yorkers. Consumer feedback is critical to SNP success because, after all, SNPs are about supporting people and ensuring their health care needs are met.

# Appendix A: Resources

## General SNP Information

### **SNP Tips: A Guide for Advocates to New York State's HIV Special Needs Plans**

<http://www.gmhc.org/policy/benefits/snip-tips.pdf>

### **New York State Department of Health**

<http://www.health.state.ny.us/nysdoh/hiv aids/snps/index.htm>

### **New York Medicaid Choice**

1-800-505-5678, or TTY/TDD: 1-888-329-1541

## SNP Contact Information

### **CommunityCare Partners, Inc. (not yet enrolling members)**

Call (212) 293-9190 for more information.

Proposed network includes: Bronx, Brooklyn, Manhattan,

### **Fidelis Care New York Healthier Life (no longer in operation)**

Member Services Number: 1-888-FIDELIS

Current network includes: Bronx, Brooklyn, Manhattan, Queens, Staten Island

### **HealthFirst PHSP, Inc. (no longer in operation)**

Member Services Number: 1-800-905-5445

Current network includes: Bronx, Brooklyn, Manhattan, Queens

### **MetroPlus Health Plan Partnership in Care**

Member Services Number: 1-800-475-METRO

Current network includes: Bronx, Brooklyn, Manhattan, Queens

### **NewYork-Presbyterian System SelectHealth, LLC.**

Member Services Number: 1-866-469-7774

Current network includes: Bronx, Brooklyn, Manhattan

### **VidaCare**

Member Services Number: 1-800-556-0689

Current network includes: Bronx, Brooklyn, Manhattan

# Appendix B: Data Sources

Gay Men's Health Crisis sincerely thanks the New York State AIDS Institute for generously sharing the data from both the Memorial Sloan-Kettering Cancer Center and IPRO surveys. Like all studies, these are not without their limitations, and they should be considered when evaluating the data. These limitations include: the small sample size of SNP enrollees, the fact that SNPs are likely composed of more health care savvy consumers who may be more adequately prepared to deal with the rigors of changing their system of care, and the fact that enrollees are paid to participate in the Memorial Sloan-Kettering Cancer Center study.

## *Memorial Sloan-Kettering Cancer Center Data*

Under Dr. Bruce Rapkin, Memorial Sloan-Kettering Cancer Center is conducting an ongoing survey of SNP enrollees. In the study outlined in this report, of the 674 enrollees eligible for the survey, 200 (30%) completed the interview. Enrollees were interviewed 45 days after their first point of contact with SNP enrollment and were

questioned about their knowledge of SNP enrollment, reasons for choosing a SNP, and level of satisfaction with the enrollment issues. The survey was commissioned by the Department of Health and data reported are as of June 1, 2004.

## *IPRO Data*

IPRO is an independent, not-for-profit corporation whose mission is to assess and improve the value of health care services received by consumers through the use of innovative methods and technologies. In an analysis report commissioned by the Department of Health, IPRO reported on the evaluation

of clinical status (verification of HIV status) of SNP enrollees and initial SNP activities (including new enrollee orientation, PCP assignment, and case manager assignment). The report issued was the result of 865 enrollee reviews completed through August 2004. For more information on IPRO go to [www.ipro.org](http://www.ipro.org).

## *QARR Data*

In New York managed care performance data is provided to the New York State Department of Health's Office of Managed Care. Collectively known as the Quality Assurance Reporting Requirements (QARR) these data are a series of measures that evaluate plan performance in a variety of areas, such as the effectiveness of care, access/availability of care, and consumer satisfaction with the experience of care. The State Department of Health makes the QARR report available to managed care

plans, providers, purchasers, and consumers as part of the Department's overall strategy to improve the quality of care provided to New Yorkers by managed care plans and to increase accountability to the public.

HIV specific QARR measures are evaluations of SNP providers. Current measures in place for these plans (2004 measures) include ARV management, adherence to ARV therapy, and HIV

monitoring. Over the course of the next two years additional measures will be added to the survey. These include:

Year 2: Cervical cancer screening, Chlamydia Screening, Syphilis Screening, Mental Health Screening (Adult), Chemical Dependence Assessment

Year 3: Childhood Immunizations, Gonorrhea Screening, MAC and PCP Prophylaxis, Pelvic Exam, PPD Screening, Lipid Screening, Baseline Assessment Initiation and Complete Medical Evaluation

Whenever possible, QARR measures are compared to national averages and goals. This allows plans to be compared on quality issues to the statewide or national average. It will not be possible to perform these tests with HIV specific QARRs because SNPs are only operational in New York City.

There are no QARR data available yet for the SNPs.

# References

- 1** New York State Department of Health's Medicaid enrollment website: <http://www.health.state.ny.us/nysdoh/manicare/medicaid/main.htm>
- 2** The model contract sets out the terms and conditions for SNP operations. It can be found at <http://www.health.state.ny.us/diseases/aids/resources/snps/docs/entirecopy.pdf>
- 3** New York State Department of Health, AIDS Institute, June 2004. See Appendix B.
- 4** New York State Department of Health, AIDS Institute, June 2004. See Appendix B.
- 5** IPRO Review Analysis Report, August 2004. Data obtained from New York State Department of Health, AIDS Institute. See Appendix B.
- 6** Freedman, Jay. "The New York State Response: Case Management for Persons Living with HIV and AIDS." *A History of AIDS Social Work in Hospitals*. Barbara Willinger and Alan Rice, editors. Binghamton, NY. Haworth Press, 2002. Page 66.
- 7** New York State Department of Health, AIDS Institute, Case Management Standards for Community Based Programs, page i.
- 8** SNP model contract, section 10.12.
- 9** See Appendix B for more information about QARR measurements.
- 10** SNP model contract, section 16.

*Gay Men's Health Crisis (GMHC) is a not-for-profit, volunteer-supported and community-based organization committed to national leadership in the fight against AIDS. Our mission is to reduce the spread of HIV disease, help people with HIV maintain and improve their health and independence, and keep the prevention, treatment and cure of HIV an urgent national and local priority. In fulfilling this mission, we will remain true to our heritage by fighting homophobia and affirming the individual dignity of all gay men and lesbians.*

*For copies of this report, please call 212/367-1228.*

*For information about our educational materials, please call GMHC Publications: 212/367-1205. For all other information, please call the Hotline or visit our website.*

**GAY MEN'S HEALTH CRISIS**

**The Tisch Building  
119 West 24 Street  
New York, NY 10011**

**AIDS HOTLINE:**

**1-800-AIDS-NYC (1-800-243-7692)**

**IN NYC: 212/807-6655**

**E-MAIL: [hotline@gmhc.org](mailto:hotline@gmhc.org)**

**WEBSITE: [www.gmhc.org](http://www.gmhc.org)**

