

Minority AIDS Initiative Outcome Evaluation

Access to Care and
Maintenance in Care Programs

- BACKGROUND ON THE EVALUATION -

Prepared for the New York HIV Planning Council
Data Day 1
January 21, 2005

The New York Academy of Medicine



The Minority AIDS Initiative

- **The Minority AIDS Initiative (first known as the “Congressional Black Caucus Initiative”) began in 1998 in response to the HIV/AIDS crisis in racial and ethnic minority communities in which HIV was having a disproportionate impact.**
- **Minority AIDS Initiative (MAI) funds support three areas: technical assistance and infrastructure support, increasing access to prevention and care, and building stronger community linkages to address the HIV prevention and health care needs of specific populations.**
- **The federal government requires ongoing outcome evaluation for activities supported by MAI funds.**

Programs in the Evaluation

- Within the federal parameters for use of MAI funds, the New York HIV Planning Council identified several areas to support, including enhancing access to care for racial and ethnic minorities with HIV and helping persons in this population who are in care sporadically to stay in care more consistently.
- The outcome evaluation based at the New York Academy of Medicine (NYAM) focuses on 23 Access-to-Care (ATC) and Maintenance-in-Care (MIC) programs supported by MAI funds through the New York HIV Planning Council process.
- Nineteen programs are in New York City and four are in Westchester County.

Programs in the Evaluation

- **Access to Care (13 programs)**

Community based organizations and health care organizations that provide outreach and referral services to members of the target population who are not in care.

- **Maintenance in Care (10 programs)**

Health care organizations that provide intensive follow up and supportive services to help members of the target population stay connected to care.

Programs in the Evaluation

Site Type by Program Type

	Access to Care	Maintenance in Care
Community-Based Organization	6	0
Community Health Center	2	3
Hospital	5	7

Key Features of Evaluation

- Outcome and process evaluation
- Longitudinal (ongoing, with multiple measures at different time points of the same clients)
- Universal sample of all clients enrolled in the 23 ATC and MIC programs. Although the sample is not representative of all people living with HIV in New York, it appears to be somewhat representative of people of color living with HIV in New York *who are in care.*

Collaborative Process for Development of Evaluation

- **Assembled all grantees and administrative agencies.**
- **Identified core constructs.**
- **Developed instruments and piloted them.**
- **Trained program staff (ongoing).**
- **Meet on an ongoing basis to discuss analyses, findings and ongoing problem-solving.**

Evaluation Objectives

- 1. Describe change in functional health status for different populations and groups of clients.**
- 2. Assess whether programs meet intermediate objectives (decreased drug use, increased service use, improved housing stability) over time.**
- 3. Identify services or constellations of services associated with intermediate outcomes, access to and maintenance in care, and change in functional health status over time.**

Types of Data Analysis

- 1. BASIC DESCRIPTION:** basic characteristics of the client population at baseline.
- 2. CHANGES OVER TIME:** amount of change in certain measures over time. For example, “did clients’ functional health status improve or decline between baseline and the 1st quarterly interview?”

Types of Data Analysis

- 3. SERVICE UTILIZATION:** intensity of clients' use of services.
- 4. RELATIONSHIP OF PROGRAM CHARACTERISTICS TO OUTCOMES:** what is the relationship between program characteristics and changes in outcome measures? Are certain program characteristics related to positive changes in health status, access to care and maintenance in care?

Client-Level Data Collection

- All client-level evaluation forms are completed by front-line service providers at each program site. These providers are trained by NYAM.
- When a new client intake takes place, an “initial encounter” form is completed. This form captures the services provided at the first encounter and basic demographic information.
- Each time a client is provided with a service, this is documented using a “follow-up encounter” form.

Client-Level Data Collection

- Within one month of intake, a comprehensive **baseline assessment** is completed.
- Clients are then reassessed every quarter (3 months) using a **quarterly assessment** tool.
- When a client's case is closed, a “**data collection closure**” form is completed.

Baseline and Quarterly Assessments: Data Elements

- **Biological Markers**
 - HIV Status, Viral Load, T-Cell Count
 - History of opportunistic infection
- **Demographic Characteristics**
 - Race
 - Gender
 - Country of Birth
 - Education Level
 - Primary Language
 - Age (Birth Date)

Baseline and Quarterly Assessments: Data Elements

- **Barriers to Care**
- **Social Support**
- **Substance Use and Treatment**
 - **Past and Current Drug Use**
 - **Utilization of Harm Reduction Services**
 - **Utilization of Drug Treatment Services**

Baseline and Quarterly Assessments: Data Elements

- **Adherence to Treatment**
 - Adherence Rate
 - Reasons for Missing Doses
- **Housing status**
- **Household composition**
- **Incarceration history**

Baseline and Quarterly Assessments: Data Elements

- **Receipt of HIV Information**
- **Sources of Income**
- **Zip Code**
- **Functional Health Status**

Functional Health Status

- **Used in this evaluation as one of the primary measure of final “outcomes”**
- **One of the most widely used health status measurement tools in HIV research. Validated in numerous studies.**
- **Compared to biological markers (such as viral load), functional health status is more closely linked to the objectives of ATC and MIC programs**
- **Does not require access to medical records**
- **Relies on clients’ self-report about their feelings and their ability to accomplish daily life tasks**

Functional Health Status: Main Components

- ☞ **General Health Perception**
- ☞ **Physical Functioning**
- ☞ **Role Functioning**
- ☞ **Social Functioning**
- ☞ **Cognitive Functioning**
- ☞ **Pain**
- ☞ **Mental Health**
- ☞ **Vitality/Energy**

Program-Level Data Collection

- **SITE VISITS:** NYAM research staff visit all program sites to conduct qualitative interviews with program staff about their program design, staffing, etc. Site visit information is updated annually.
- **FOCUS GROUPS:** Focus groups are conducted with program staff periodically. A set of focus groups was conducted on reasons for clients' leaving the programs (to understand client attrition and its impact on the sample) and on programs' "best practices."
- **MONTHLY MEETINGS:** Program staff provide input on the evaluation at monthly evaluation meetings, which all programs are required to attend.
- **PROGRAM CHARACTERISTICS WORKSHEET:** Programs work collaboratively with NYAM staff to define their key program characteristics for use in data analysis.

Program Characteristics Worksheet: Data Elements

- **Services available**
 - HIV primary care
 - Drug treatment
 - Mental Health
 - # of co-located services
- **Staffing**
 - Size of project team
 - Staff turnover
 - # of peer workers

Program Characteristics Worksheet: Data Elements

- **Service setting**
 - ATC vs. MIC
 - Hospital vs. CBO
 - Medical vs. non-medical
 - Source of clients (street outreach, in-reach, etc.)
 - Point of service delivery (hospital, homeless shelter, etc.)

Baseline Characteristics of All Enrollees

Characteristics		Percent of All Enrollees (n=4003) %
Gender	Female	38
	Male	61
	Transgender	1
Race/Ethnicity	Black	58
	Latino/Hispanic	37
	White	3
	Asian/Pacific Islander	<1
	Native American	<1
	Other/Mixed	2
Borough	Bronx	32
	Brooklyn	25
	Manhattan	32
	Queens	3
	Staten Island	<1
	Westchester	6
	Other	1
HIV Status	HIV Positive	69
	Unknown	31

Data through December 2004. Missing data not shown.

Change in Functional Health Status

Baseline to 1st Quarterly Follow-Up

	All Sites (n = 1791)
Domain	Mean % Change
General Health Perception	25.9*
Physical Functioning	11.4*
Role Functioning	8.7*
Social Functioning	14.7*
Cognitive Functioning	16.1*
Pain	15.0*
Mental Health	25.2*
Vitality/Energy	21.6*

*Significant at $p < .0001$ level.

Data through December 2004

Strengths of Evaluation

Can answer questions about:

- Programs' ability to recruit targeted populations.
- Associations between program participation and improvements in health.
- Associations between program participation and achievement of intermediate outcomes.
- Associations between achieving intermediate outcomes and improvements in health.
- Which programs or program types produce the greatest improvements in health.
- Which client types show the greatest improvements in health.
- Which programs or program types are best able to retain clients in care.

Limitations of Evaluation

- It is not possible to isolate causation without an experimental design.
- Because MAI programs are often embedded in a network of services offered by an agency, it is difficult to attribute outcomes solely to MAI-funded activities.
- Measures used are based on client self-report and may be biased.
- Coupling contract monitoring with program evaluation data collection may have distorted evaluation data.
- Program-level resources required to carry out the evaluation are burdensome.
- Sample is biased by differential attrition by specific client characteristics (for example, housing status and substance use status).

Current NYAM MAI Evaluation Team

- Ruth Finkelstein, Sc.D., Principal Investigator
- John Chin, Ph.D., Project Director
- Elana Behar, M.A., Project Coordinator
- Michael Botsko, M.S.W., M.Phil., Statistician
- Anthony Lewis, B.A., Research Assistant
- Charles Clarke, B.A., Data Manager