

Report 2003_1

Strategic Plan Progress Indicators: Baseline Report

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HIV Planning Council

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C.H.A.I.N. Report

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INTRODUCTION:

During 2002 a comprehensive strategic plan for the organization and delivery of HIV/AIDS services was prepared for New York City's Title I Planning Council[1]. The centerpiece of this plan is a set of goals and objectives developed by each of the planning council's work groups[2]. For each objective, a performance measure was defined to monitor progress towards achieving each objective. For many of the objectives it was possible to construct the performance measures from CHAIN interview data. This document is the first in what is planned to be an annual series of reports summarizing the CHAIN measures assembled from annual interviews with the CHAIN cohort. Baseline values are presented for each objective, which will serve as a basis for comparing progress in achieving planning council objectives in future years.

To assist the reader in navigating through this document, a brief summary of the organization of this report is presented below. A detailed description of the CHAIN survey and its methods of data collection is included as an Appendix to this report. Definitions for each CHAIN measure were developed for the strategic plan[3]. Each measure is constructed as a dichotomy which illustrates how well CHAIN participants' experiences relate to the stated performance criteria.

Baseline statistics for each objective that follow are summarized on a single page. Objectives are organized by work groups and goals within work groups. The heading of each page identifies the work group, the objective number and a statement of the objective. The numerical prefix of the objective corresponds to the number of the work group goals. For example, Health Services Work Group Objective 1A is the first objective for Goal 1 of this work group. Readers interested in the wording of work group goals should refer to the Strategic Plan Report. The "progress indicator" for the objective is then defined and an overall baseline value is reported. Two charts complete the presentation of the baseline statistics. The upper chart presents baseline values for males and females, major ethnic groups, HIV risk categories and T-cell levels. The indicator values for the entire CHAIN sample and the subgroups are based on most recent observation for each CHAIN participant, which may have occurred between the 5th through the 8th rounds of interviews that were conducted between 1998 and 2002. The lower chart displays the trend in the indicator for the most recent rounds of CHAIN interviews. For each work group, we highlight noteworthy subgroup differences and the trend in the performance measure for the four most recent CHAIN interviews.

[1] McClain and Associates, Inc. New York EMA Comprehensive Strategic Plan for HIV/AIDS Services 2002-2005.

[2] Ibid, pp: 58-87.

[3] Ibid, pp: 96-123.

HEALTH SERVICES WORK GROUP

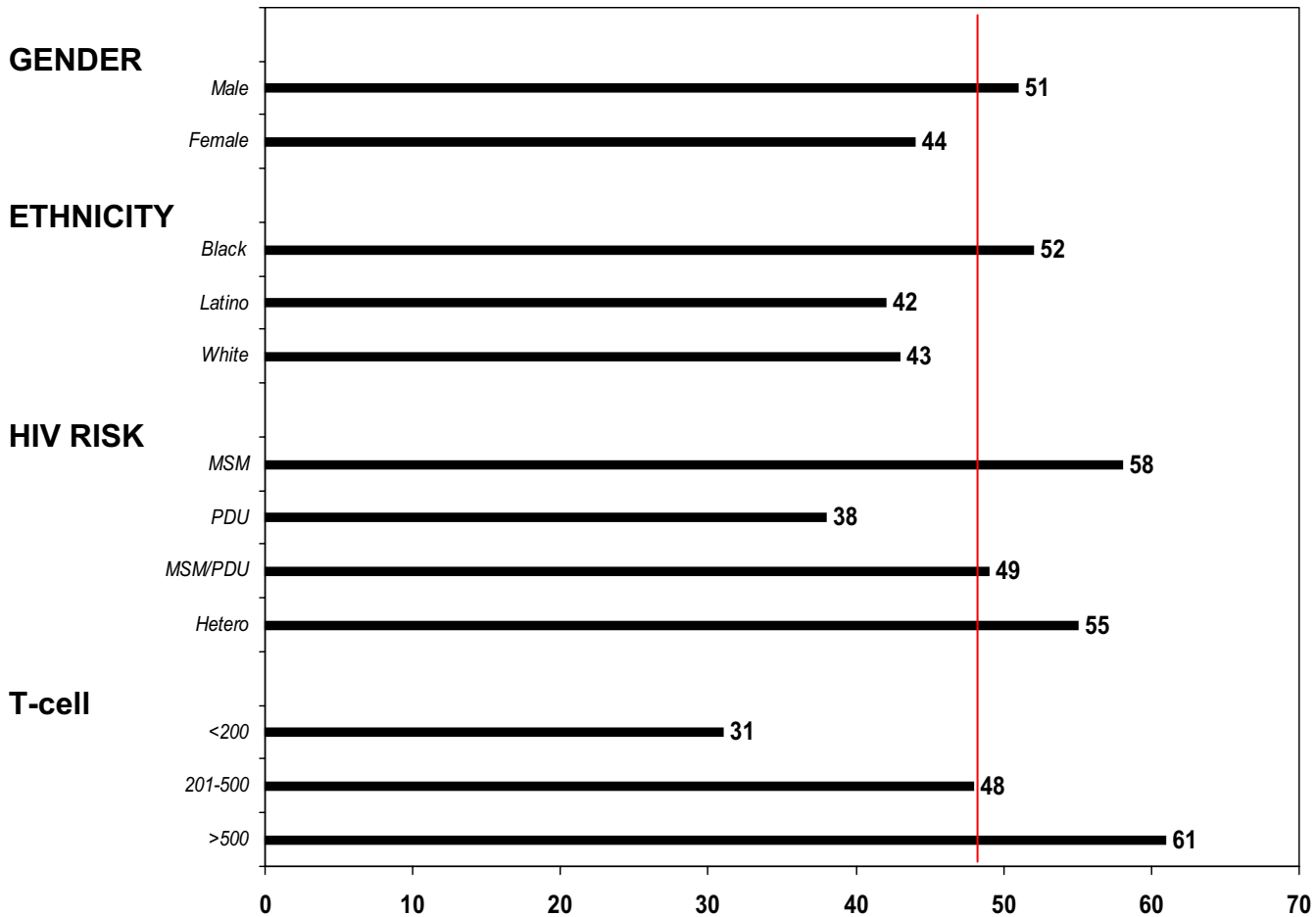
- During the period covered by the four most recent rounds of CHAIN interviews, the overall health of the study cohort has either improved (Objective 1A-2) or remained relatively stable (objectives 1A-1 and 3B)
- African-Americans in the CHAIN cohort report generally better physical health than other ethnic groups. Problem drug users are in poorer physical health than individuals in other HIV risk groups.
- Over the most recent four rounds of interviews, self-reported adherence to combination therapies has fluctuated between 56% and 67% with no discernable trend (Objective 1B). Among all subgroups, males, particularly men who have sex with men, report the highest rates of adherence.
- Trends in quality of care indicators are mixed. The CHAIN cohort report a decline in receiving medical care appropriate for HIV (Objective 3A), but the percentage of the CHAIN cohort reporting access to comprehensive medical care has increased.
- CHAIN Latinos report lower access to quality medical care than either whites or blacks.

Health Service: Objective 1A-1

Persons with HIV disease engaged in health care services will have improved survival and health outcomes.

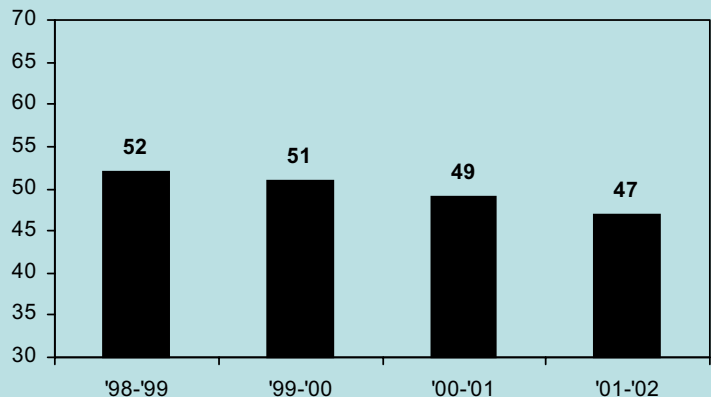
PROGRESS INDICATOR: Self-reported health status, as measured by PCS score.

BASELINE: 48 percent with PCS score of 45 or higher



1998-2002 TRENDS

Percent with PCS score 45 or above.



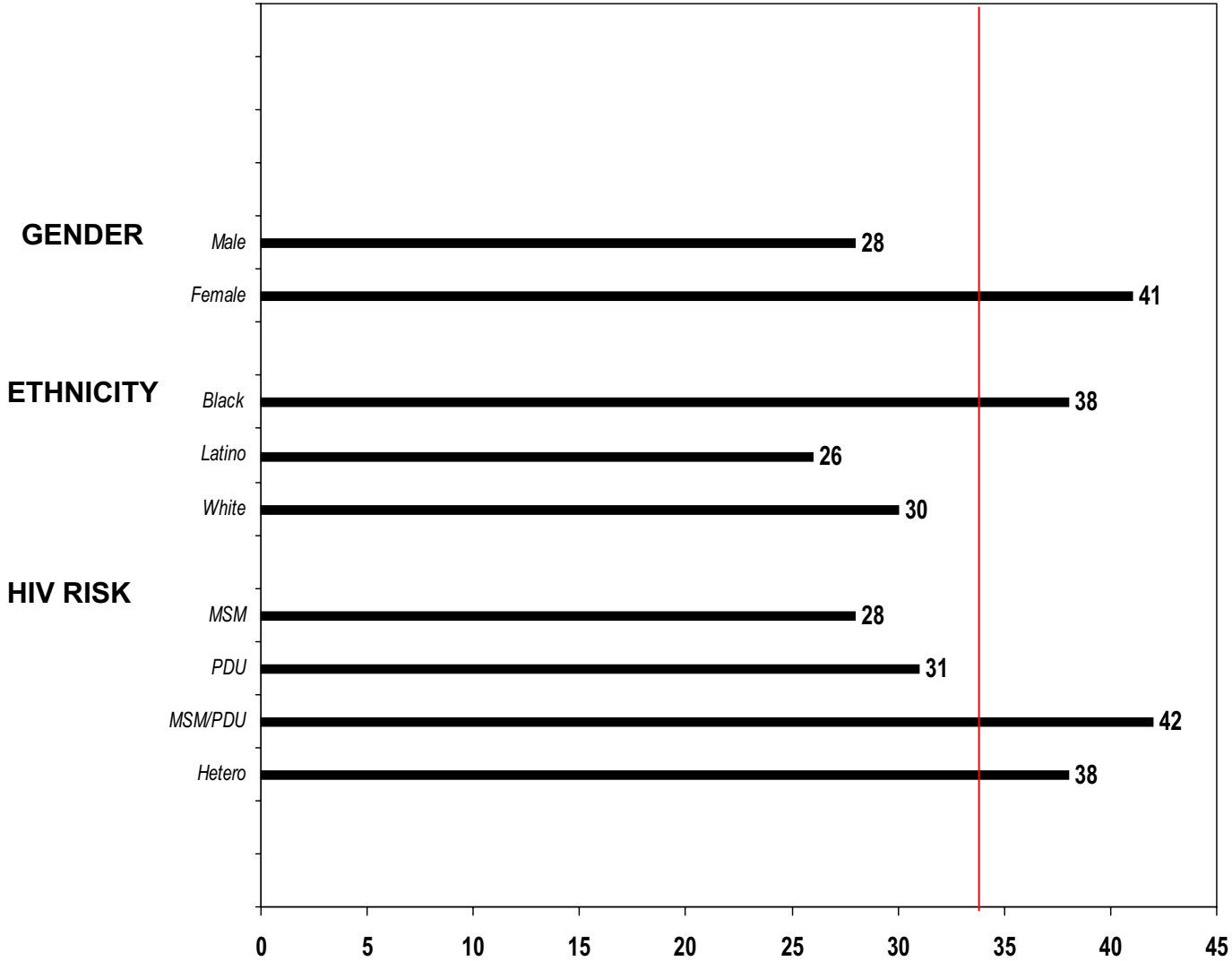
Health Service: Objective 1A-2

Persons with HIV disease engaged in health care services will have improved survival and health outcomes.

PROGRESS INDICATOR: Self-reported T-cell count.

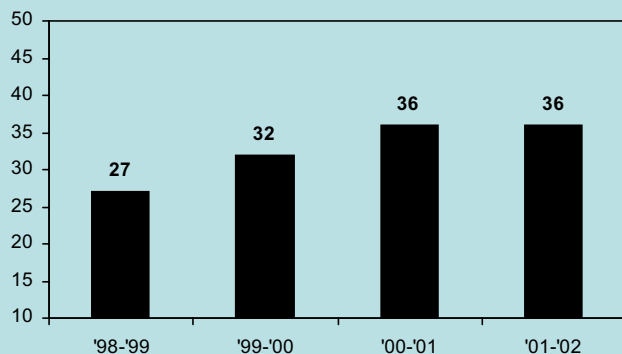
BASELINE: 34 percent (reporting T-cell count of 500+)

BASELINE



1998-2002 TRENDS

Percent reporting T-cell count of 500+.

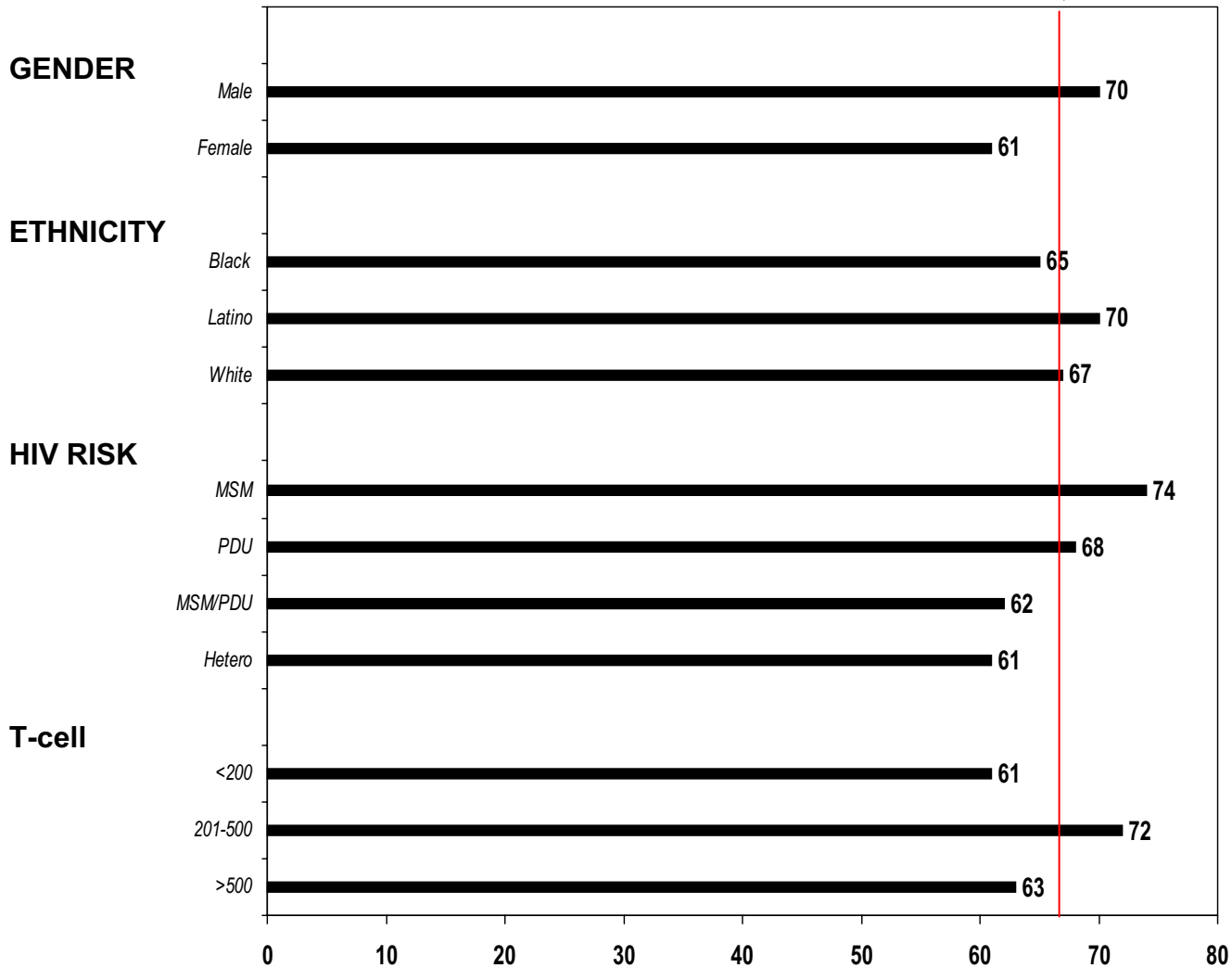


Health Service: Objective 1B

Persons who receive health services will adhere to treatments.

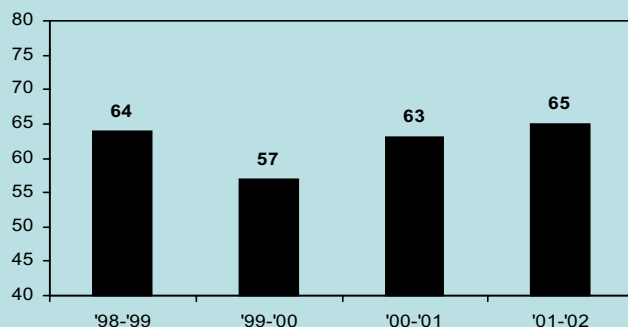
PROGRESS INDICATOR: Self-reported adherence to HIV antiretroviral medication, plus no reported missed pills in the two days prior to interview.

BASELINE: 67 percent (completely adherent)



1998-2002 TRENDS

Percent completely adherent (self-reported).



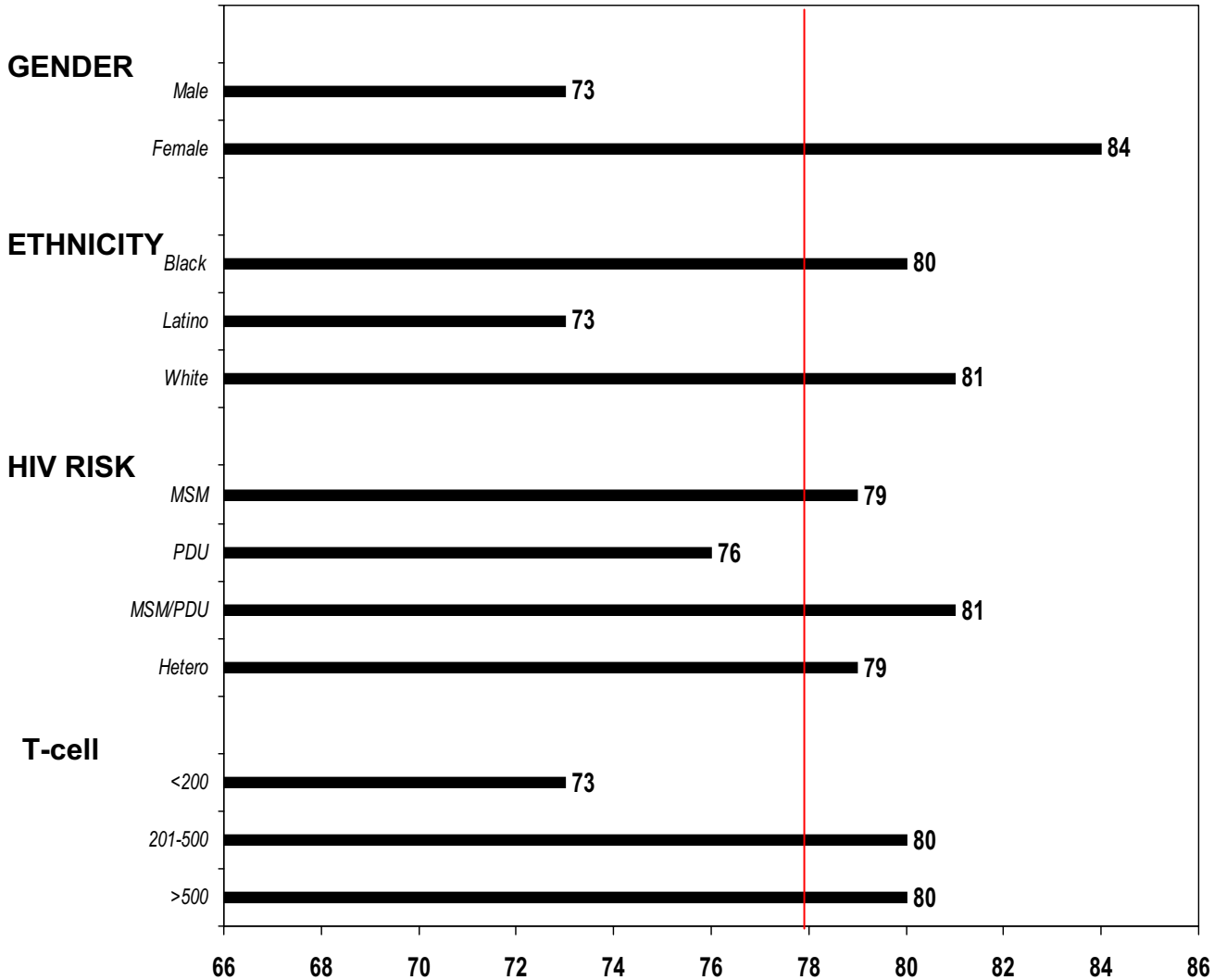
Health Service: Objective 2A

Persons with HIV disease engaged in care will remain connected to services once they have entered the continuum of care.

PROGRESS INDICATOR: Reported primary medical care doctor from same agency as last interview.

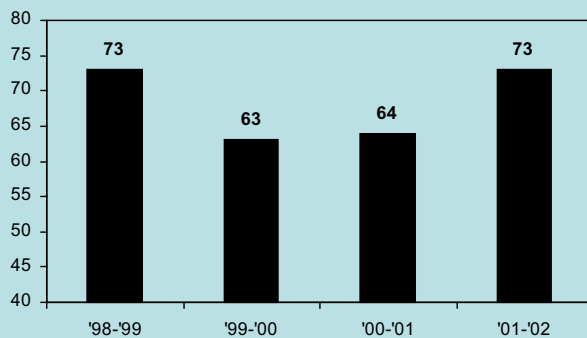
BASELINE: 78 percent

BASELINE



1998-2002 TRENDS

Percent reporting same primary medical provider as last interview.

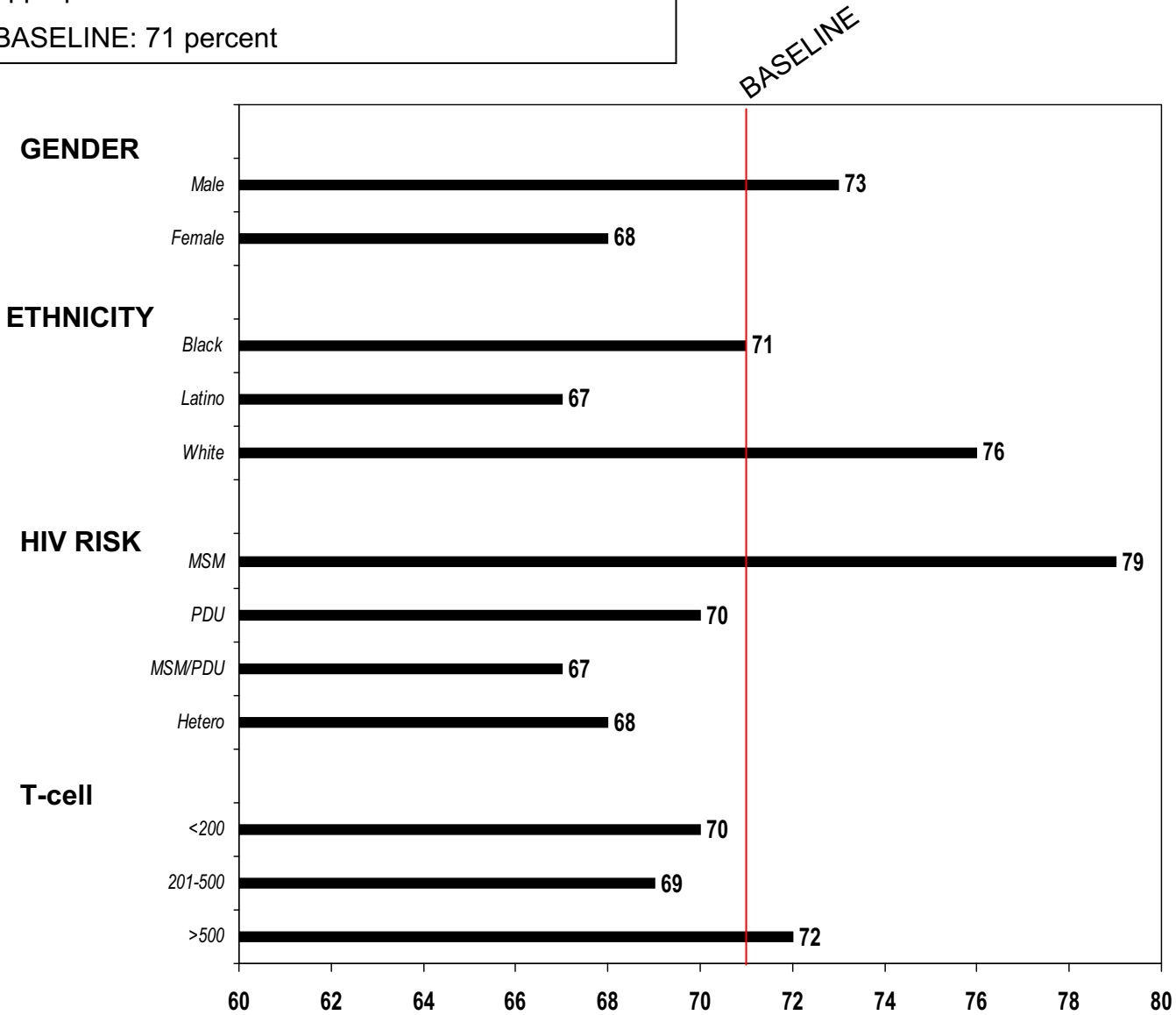


Health Service: Objective 3A

Persons with HIV disease who are in care receive services that meet or exceed the quality standards of the New York State AIDS Institute.

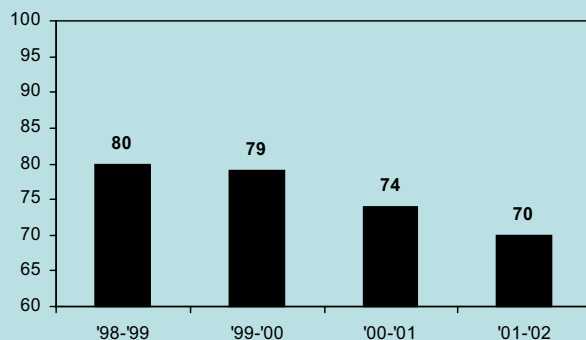
PROGRESS INDICATOR: Met 3 AI criteria for appropriate medical care.

BASELINE: 71 percent



1998-2002 TRENDS

Percent meeting AI criteria for appropriate medical care.



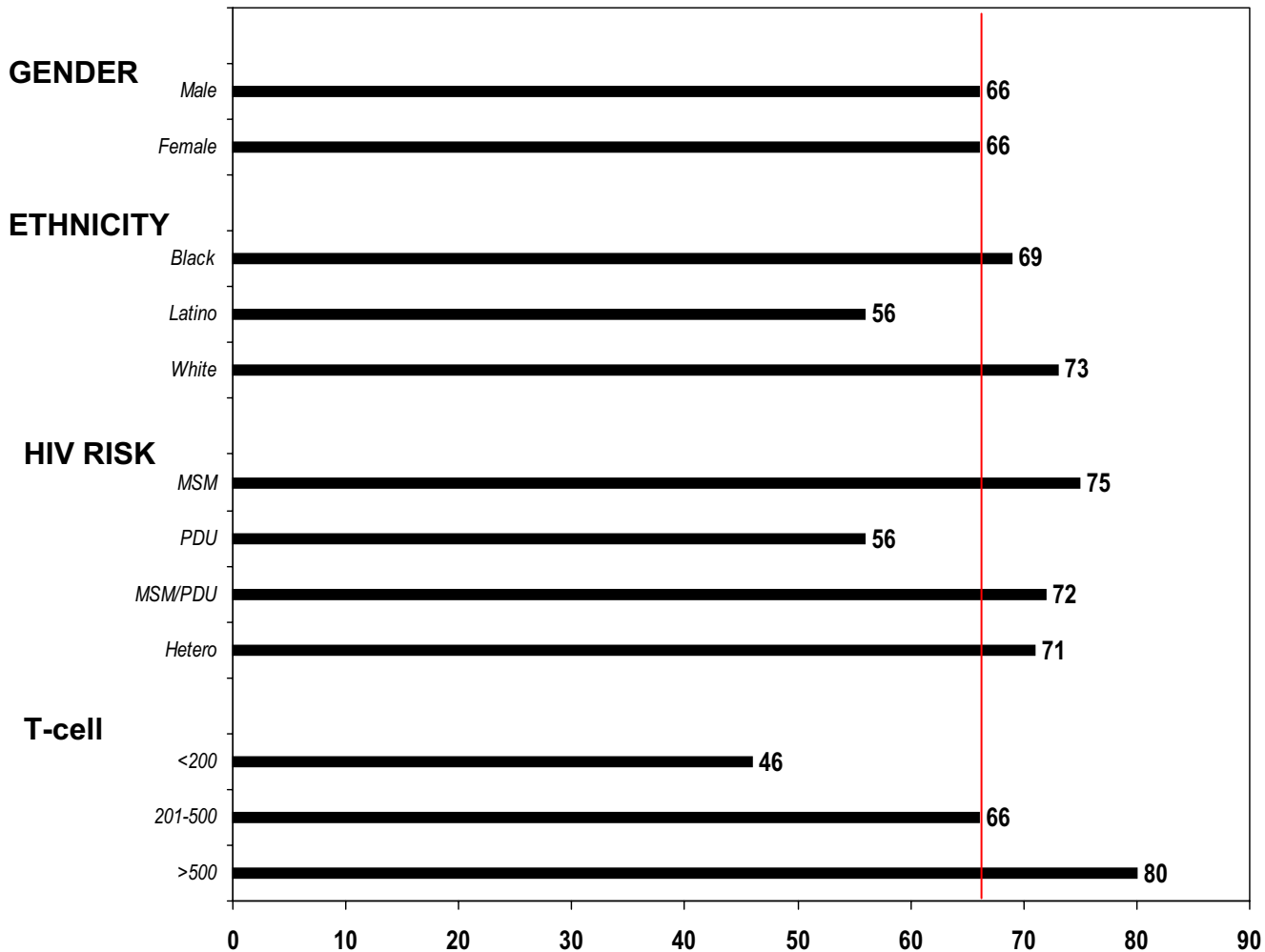
Health Service: Objective 3B

Persons with HIV disease report their health-related quality of life as “good” or better.

PROGRESS INDICATOR: Single global question measuring self-reported health status: “In general, would you say your health is excellent, very good, good, fair or poor?”

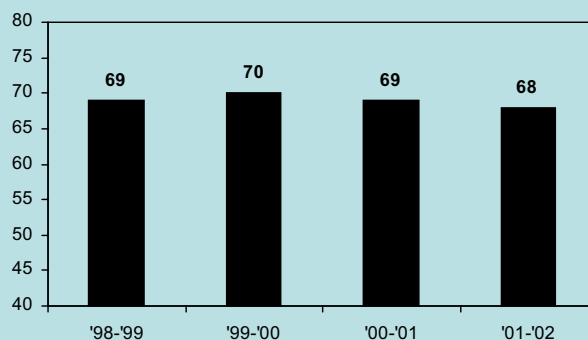
BASELINE: 66 percent (reporting “excellent,” “very good,” or “good”)

BASELINE



1998-2002 TRENDS

Self-reported health status “good,” “very good” or “excellent” (percent.)



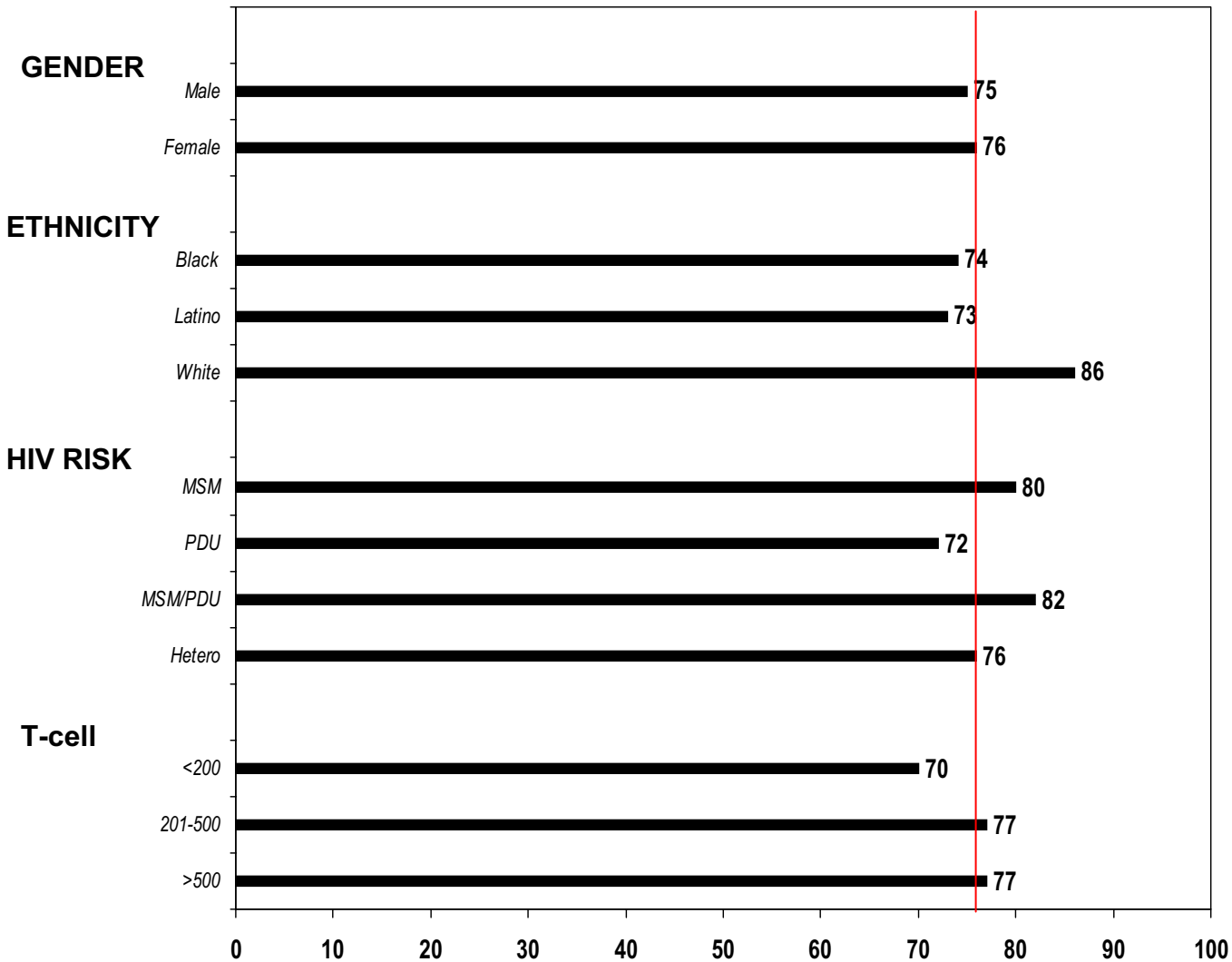
Health Service:

Comprehensive medical care.

PROGRESS INDICATOR: Respondents report receiving comprehensive medical care.

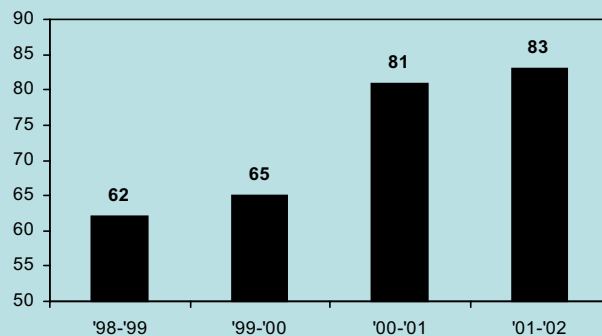
BASELINE: 75 percent

BASELINE



1998-2002 TRENDS

Percent receiving comprehensive medical care.



HOUSING WORK GROUP

- In recent interviews, the prevalence of unstable housing situations (Objective 1A) has declined, but the extent those with unstable housing conditions have received services (Objective 2A) has fluctuated from interview to interview with no real trend evident.
- Groups most at-risk for unstable housing are males, problem drug users and those with low T-cell counts.
- Among the unstably housed, those least likely to have received housing services were whites, men who have sex with men and individuals infected through heterosexual contact.

Housing: Objective 1A

Transitional housing will be available to people with HIV/AIDS who need it.

PROGRESS INDICATOR: Reported being unstably housed; any episode of living in street, shelter, single room occupancy, or doubled up with a friend or relative.

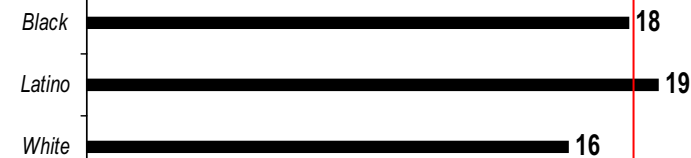
BASELINE: 18 percent

BASELINE

GENDER



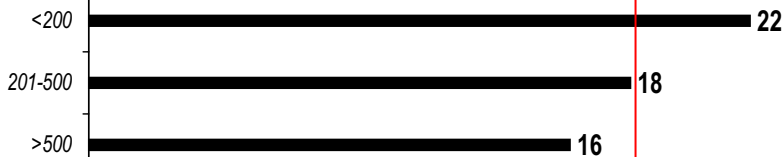
ETHNICITY



HIV RISK

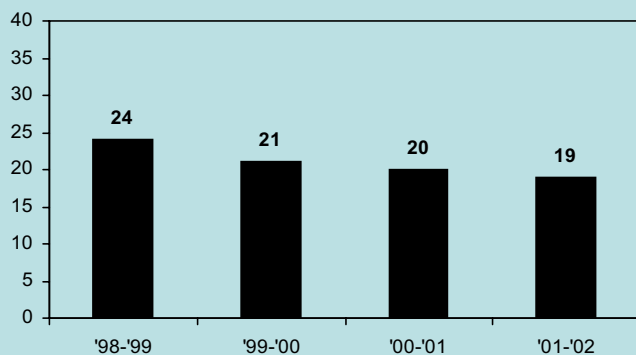


T-cell



1998-2002 TRENDS

Percent who report being unstably housed.



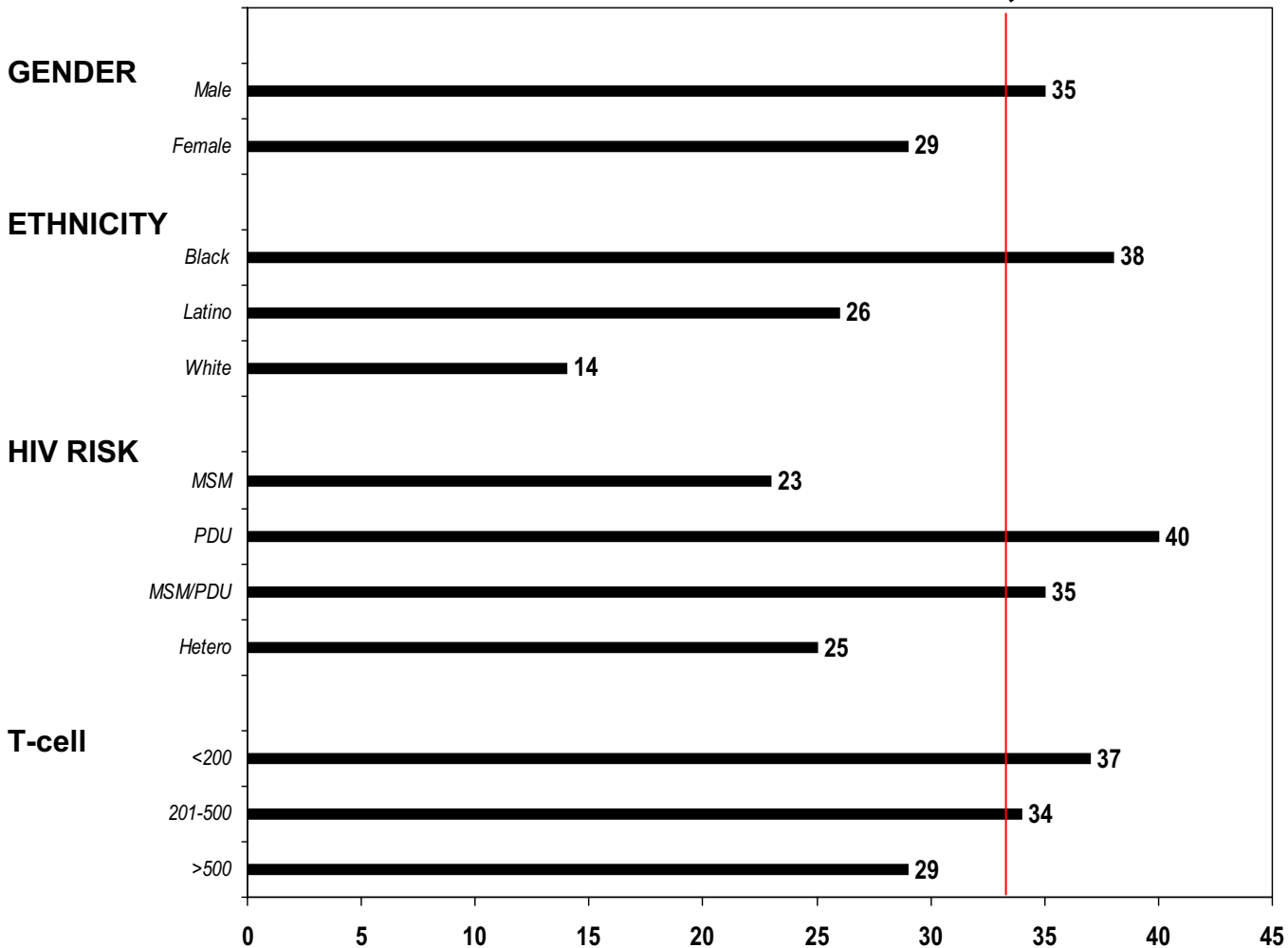
Housing: Objective 2A

Housing placement assistance services will be available for persons with HIV who need them.

PROGRESS INDICATOR: Among those who reported being unstably housed, those who received a housing subsidy, lived in specialized AIDS housing (such as scatter-site housing), or received housing services to assist with house/apartment maintenance, landlord/tenant issues, access, etc.

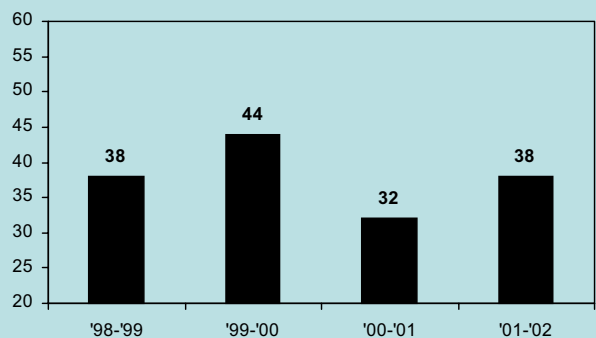
BASELINE: 33 percent

BASELINE



1998-2002 TRENDS

Percent of unstably housed who received assistance.



AOD WORK GROUP

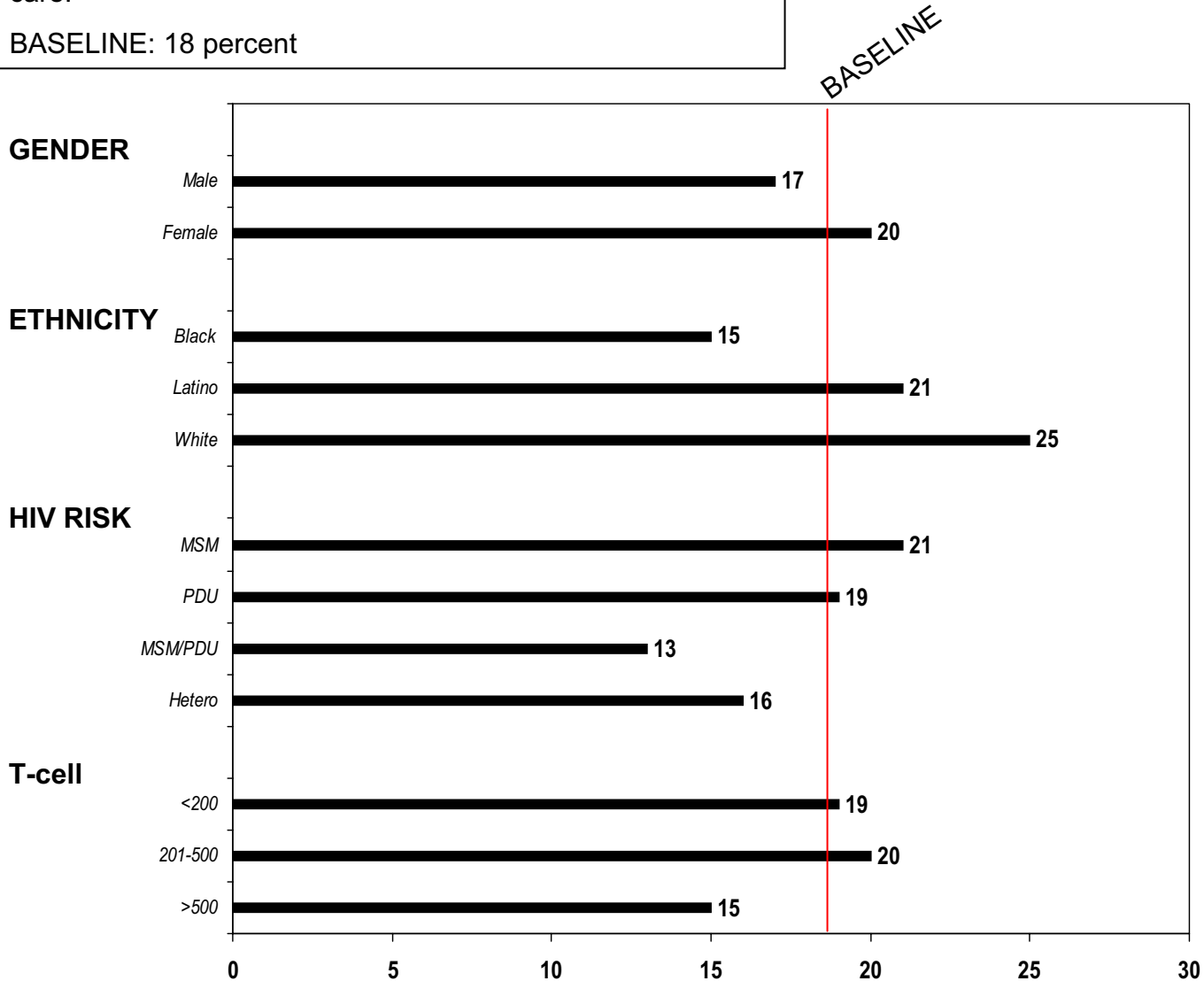
- It appears that reports of encounters with disrespectful or insensitive staff have increased in the most recent round of interviews (Objective 1A). There are no strong trends in use of mental health services among drug users in need of this service (Objective 1B).
- Among those who report current or past drug use, whites and Latinos were more likely than blacks to report encounters with disrespectful or insensitive staff.

AOD: Objective 1A

Health care/mental health and other providers will understand AOD culture and provide culturally appropriate and sensitive treatment to AOD users.

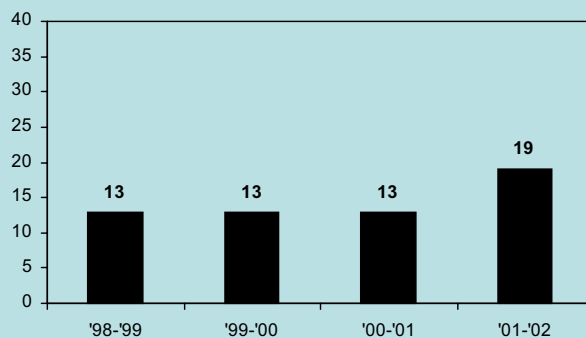
PROGRESS INDICATOR: Among those who reported current or past drug use, questions measuring barriers to care.

BASELINE: 18 percent



1998-2002 TRENDS

Percent AOD users who report barriers to care.

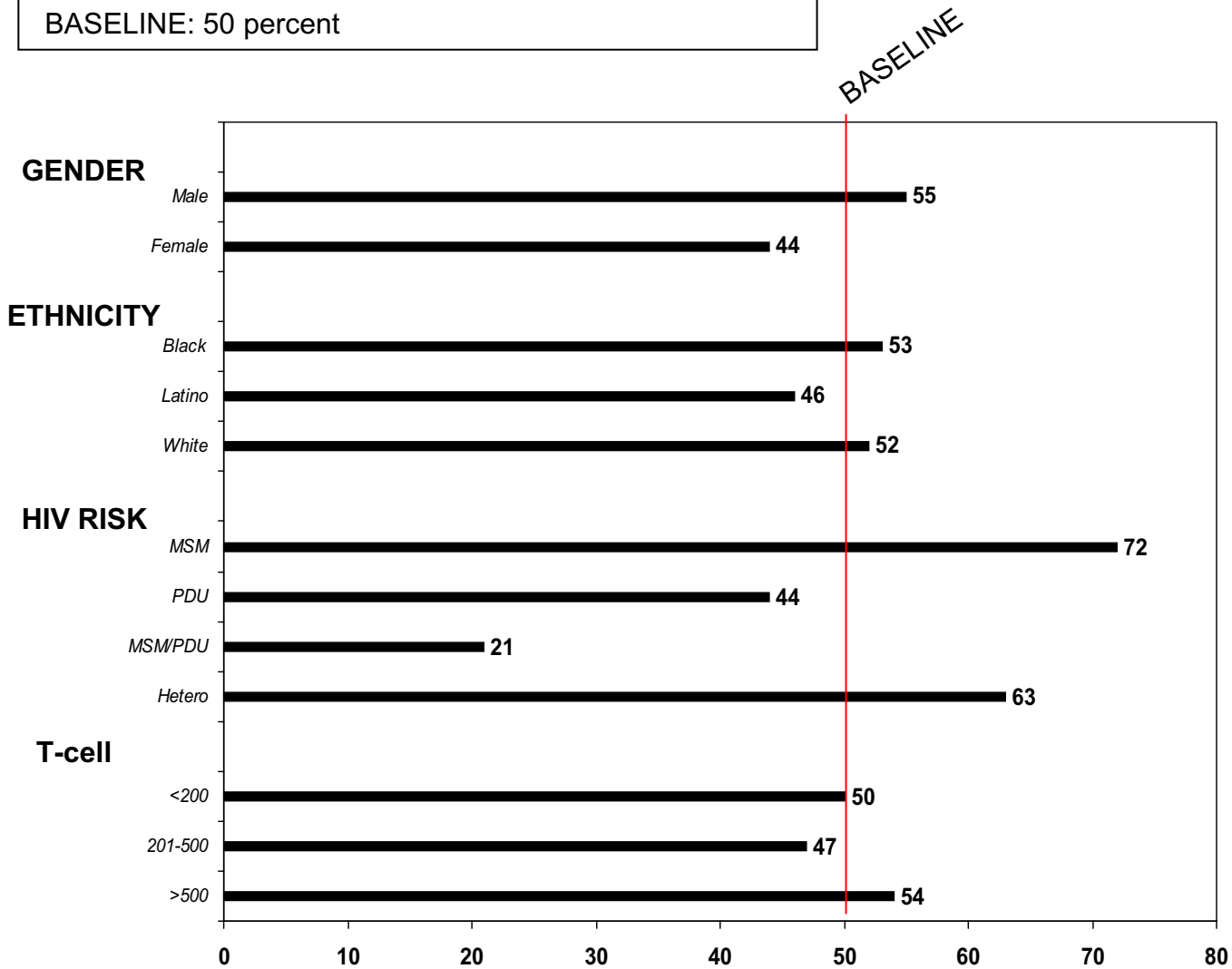


AOD: Objective 1B

Health care, mental health and other services will be more available and accessible to AOD users.

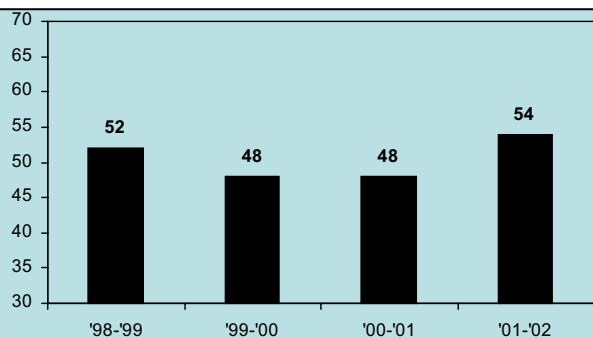
PROGRESS INDICATOR: Among those who reported current or past drug use and had objective need for mental health services, those who reported that they received professional or supportive mental health services.

BASELINE: 50 percent



1998-2002 TRENDS

Percent AOD users receiving mental health services.



INFRASTRUCTURE WORK GROUP

- The percent of CHAIN participants reporting some difficulty in locating services increased at the most recent interview (Objective 1A).
- Whites were more likely than ethnic minority groups to report experiencing delays in assistance due to a lack of information about where services are located.

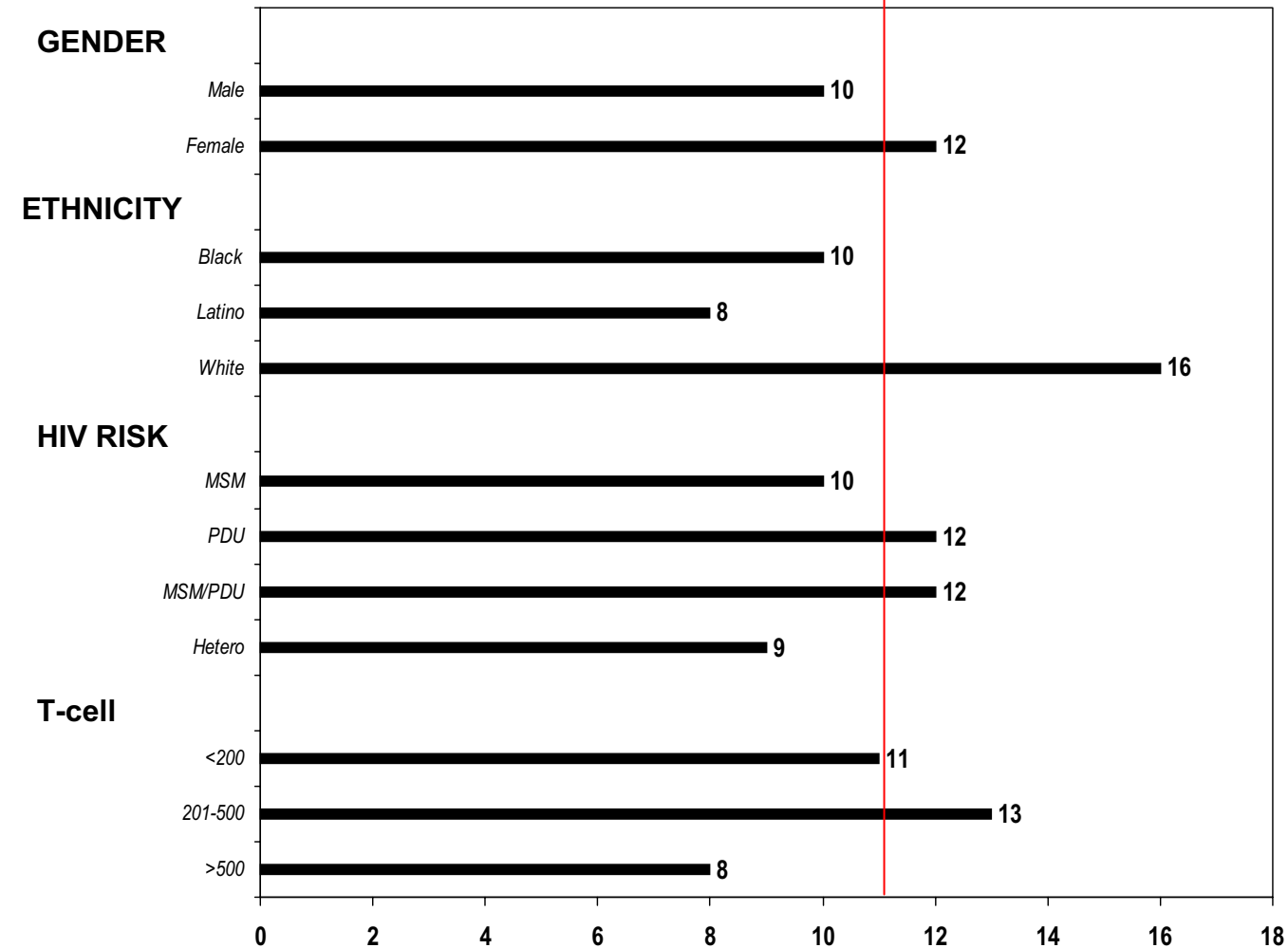
Infrastructure: Objective 1A

Appropriate information will be available on type and location of services and on options for choosing services that best meet the needs of persons with HIV.

PROGRESS INDICATOR: Questions measuring barriers to care: “Did you ever delay or not get assistance you thought you needed because . . . You didn’t know or weren’t sure where to go” for medical or social services?

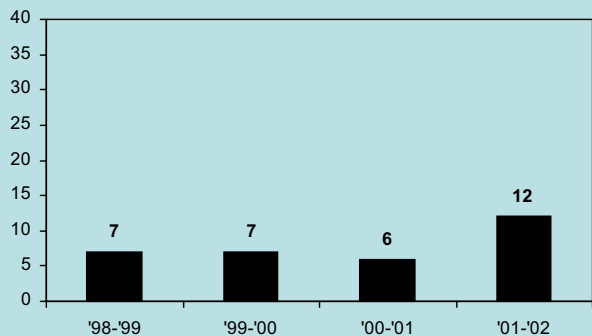
BASELINE: 11 percent

BASELINE



1998-2002 TRENDS

Percent reporting barriers to care—lack of information about location of services.



SOCIAL SERVICES WORK GROUP

- Reports of encounters with disrespectful or insensitive staff have increased in the most recent interview (Objective 1B)
- Access to transportation services (Objective 1C) and resolution of problems with a range of basic service needs (Objective 1D) have tended to improve in recent interviews.
- Among those with need for transportation services, groups least likely to receive these services were Latinos, those with low T-cell counts and those classified into the problem drug use and heterosexual HIV risk categories.
- Whites, men who have sex with men, and those with T-cell counts above 500 were most likely to report few or no problems in resolving problems involving a broad range of basic needs.
- An overwhelming majority of CHAIN participants have reported across all recent interviews that they have received helpful advice about medical treatment (Objective 3B). Similarly, among those eligible, very large percentages of CHAIN participants were on Medicaid (Objective 4A).
- White and those in the men who have sex with men/problem drug use (MSM/PDU) category were least likely to report receiving helpful advice on adhering to medical treatments.

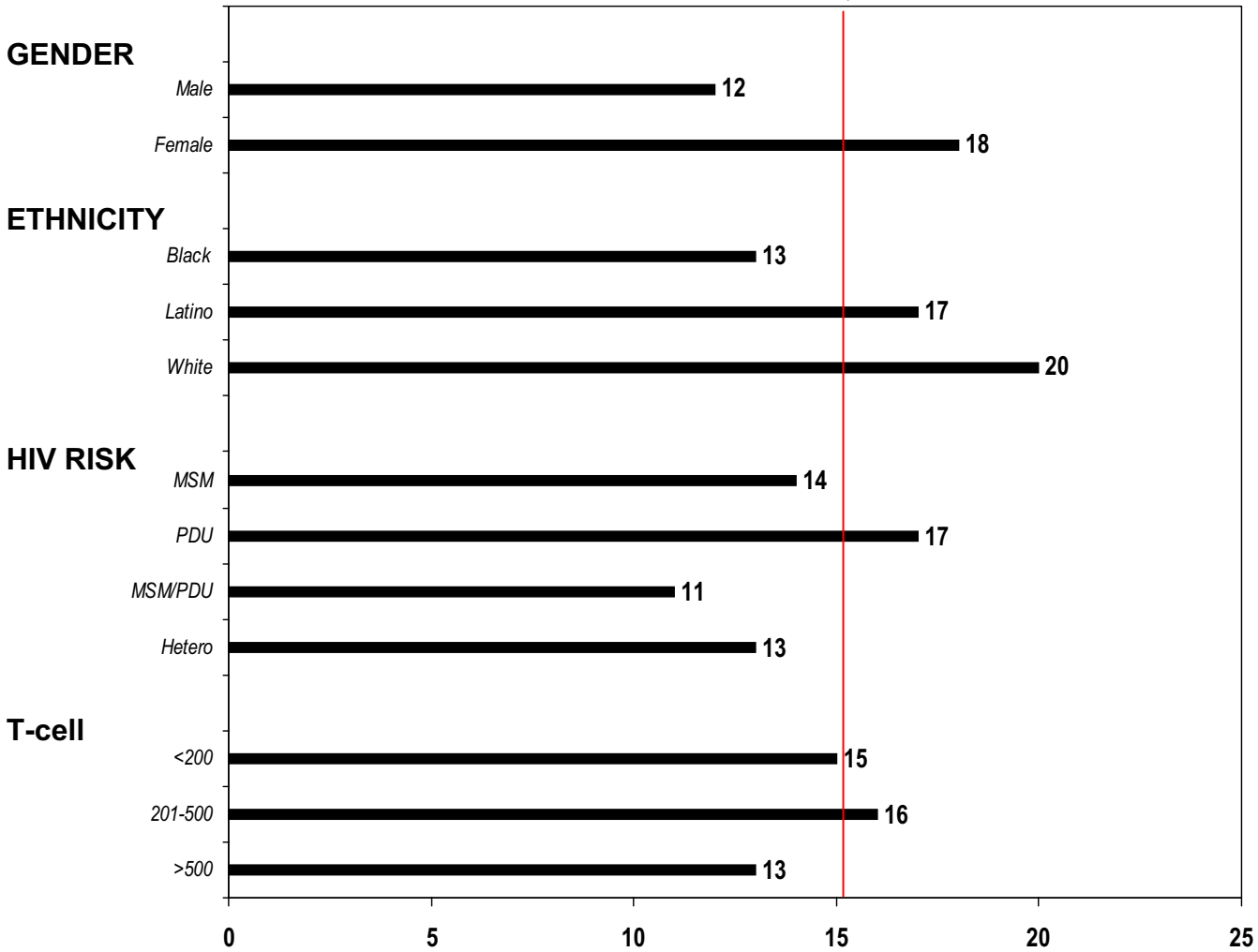
Social Services: Objective 1B

PLWH/A will have access to culturally competent and linguistically appropriate social services

PROGRESS INDICATOR: Questions measuring cultural/language barriers to care.

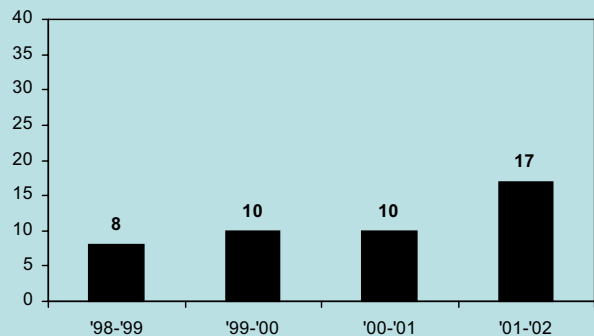
BASELINE: 15 percent

BASELINE



1998-2002 TRENDS

Percent reporting cultural/language barriers to care.

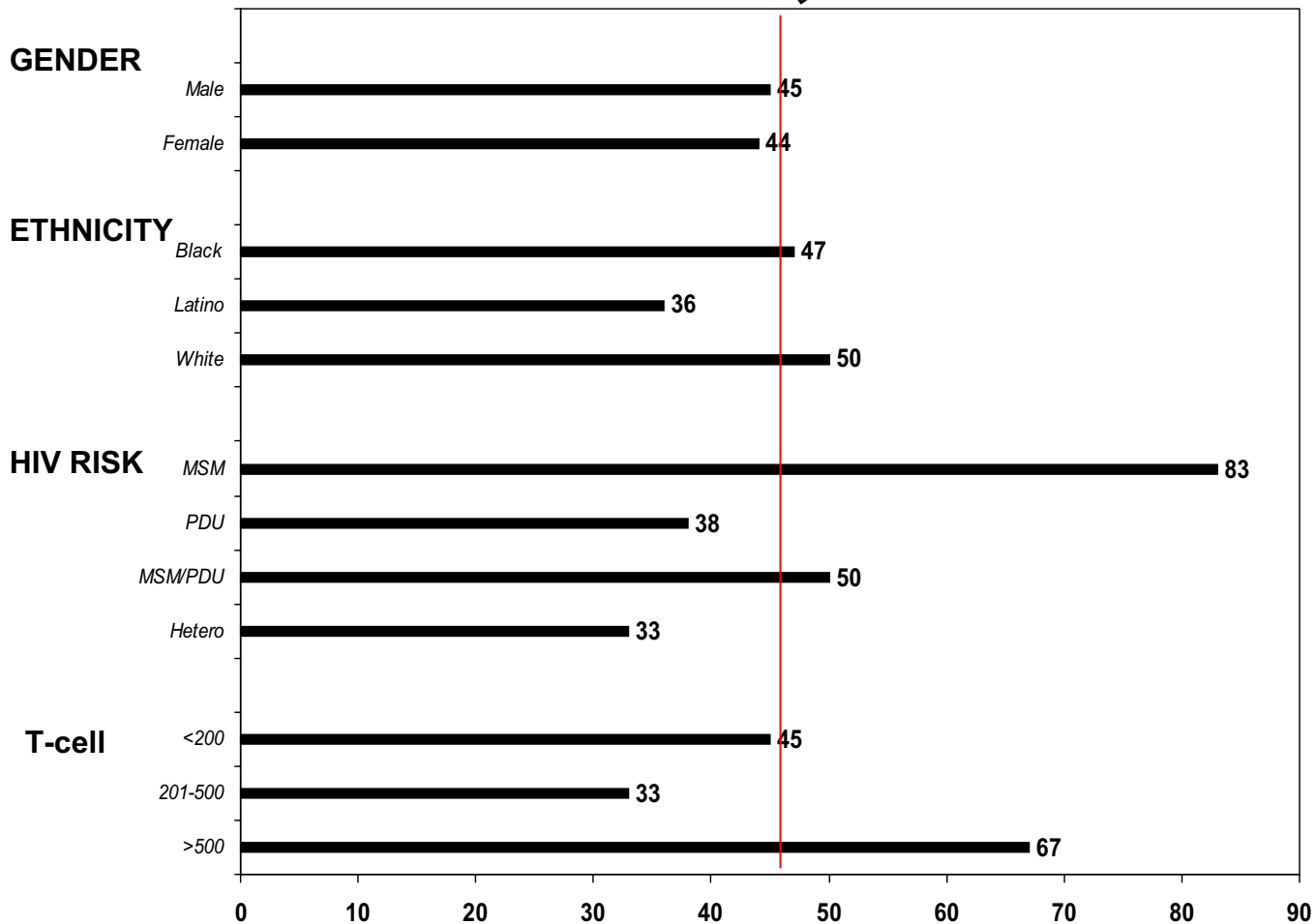


Social Services: Objective 1C

PLWH/A will have access to necessary transportation services.

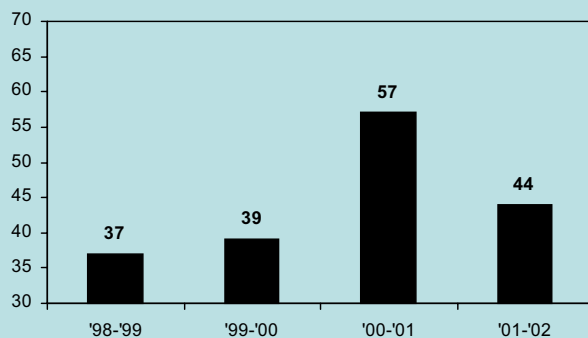
PROGRESS INDICATOR: Among those who reported needing help with transportation services or that it was a barrier in receiving care in the 6 months prior to interview, those who received transportation services.

BASELINE: 45 percent



1998-2002 TRENDS

Of those who reported transportation needs, percent who received services.



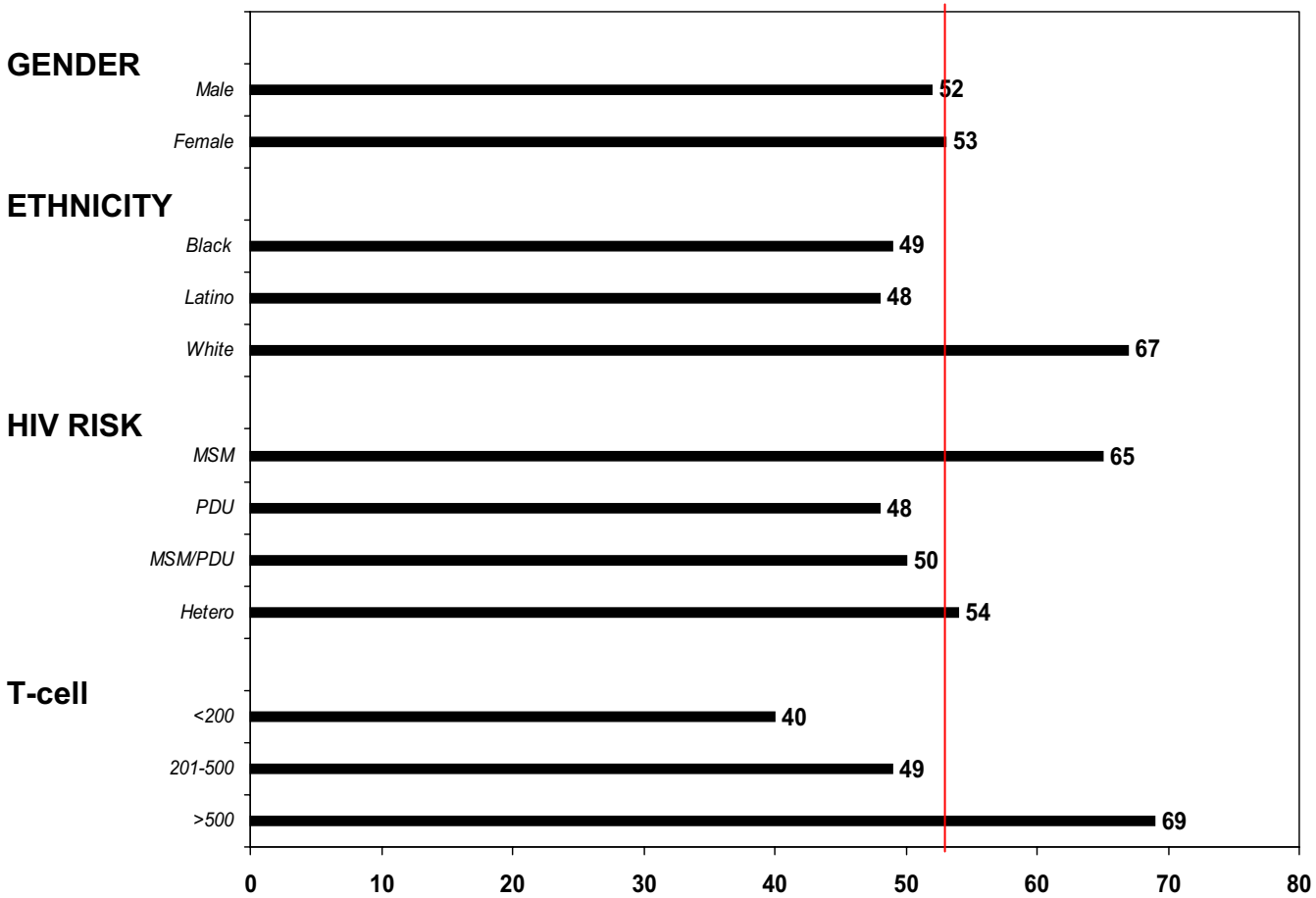
Social Services: Objective 1D

PLWH/A will have access to a broad range of support, advocacy and basic needs programs within their geographic area.

PROGRESS INDICATOR: Among those who expressed needing assistance with legal matters, child care, or food/groceries/meals, those who reported that “no change has occurred in the situation or no progress has been made” or that “the problems have been getting worse” in the respective areas.

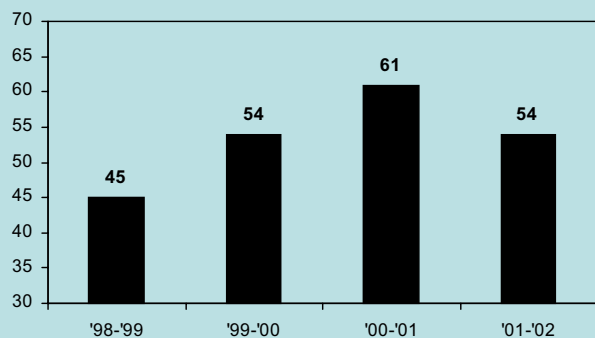
BASELINE: 53 percent

BASELINE



1998-2002 TRENDS

Percent who reported needing assistance and no change or worsening of situation.

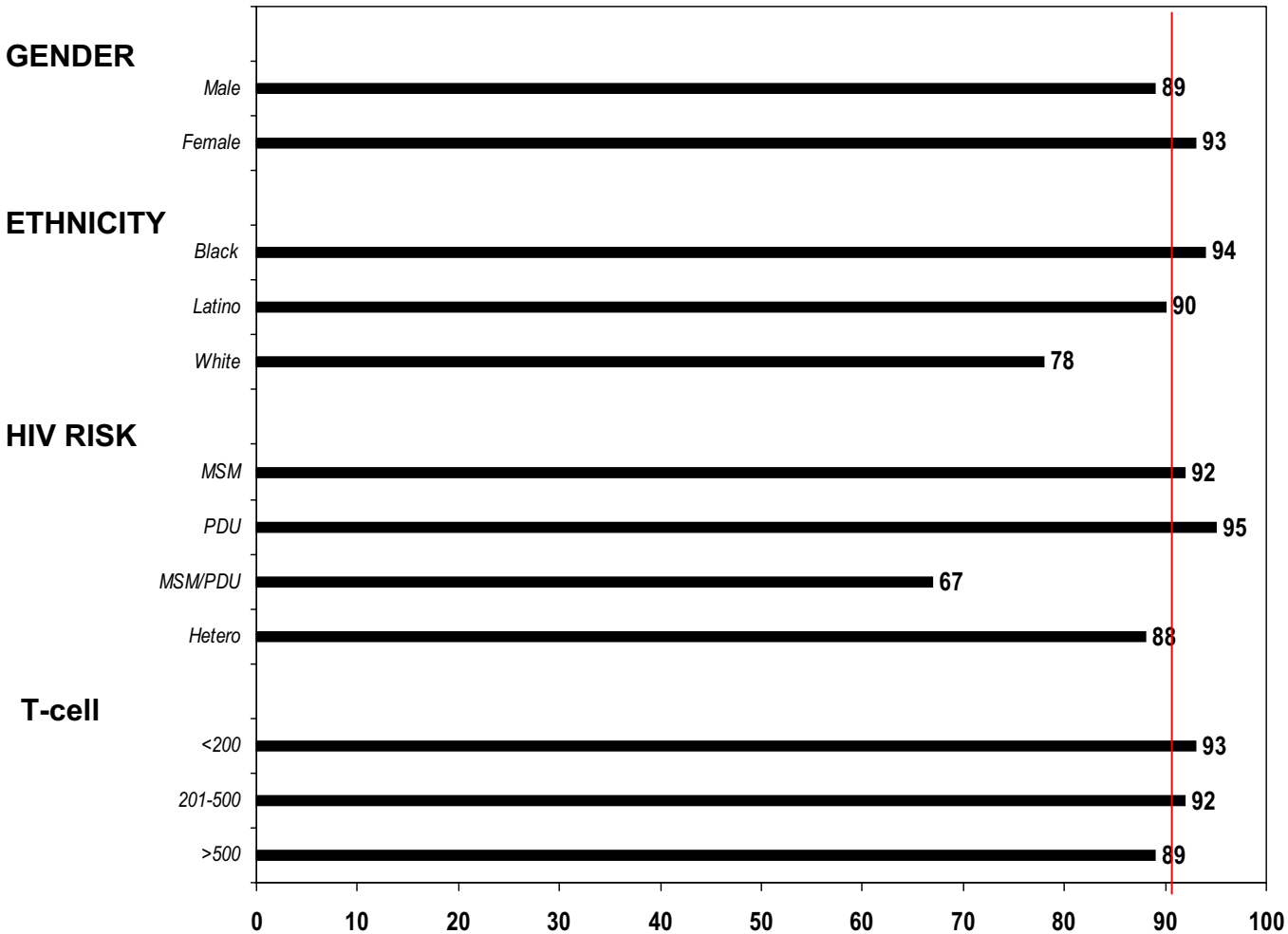


Social Service: Objective 3B

PLWH/A will have increased knowledge regarding treatment issues and adherence strategies

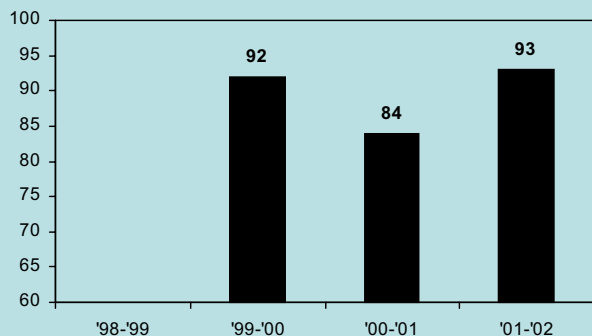
PROGRESS INDICATOR: Among those who received help with taking medication those who reported that the advice was “very helpful” or “somewhat helpful.”

BASELINE: 91 percent



1998-2002 TRENDS

Of those who reported having received help with taking medication, those who reported that such assistance had been “very” or “somewhat” helpful.



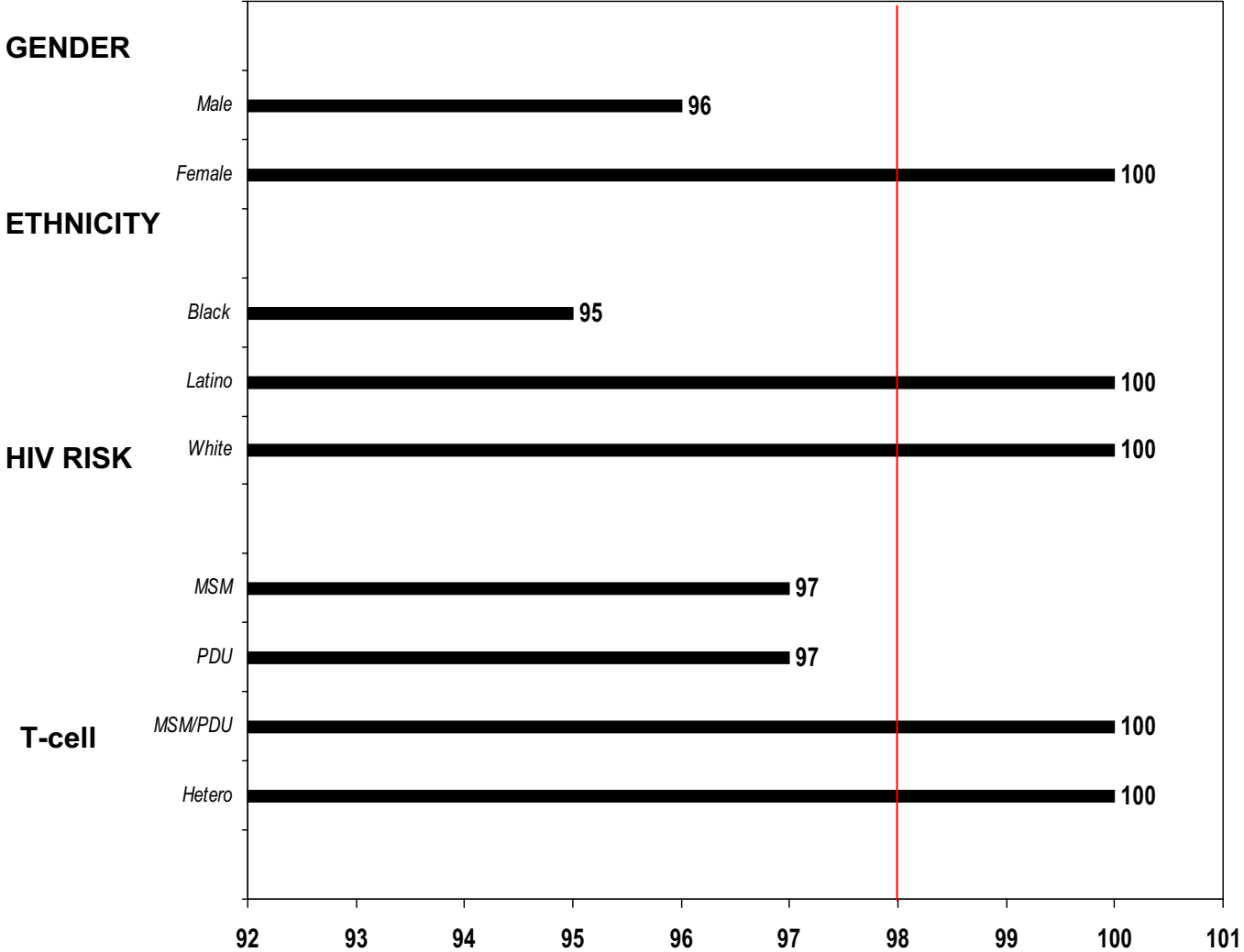
Social Services: Objective 4A

Unmet benefit need.

PROGRESS INDICATOR: Among those who had need for benefits (annual household incomes below \$10,000 and t-cell counts below 200) those who reported being on Medicaid.

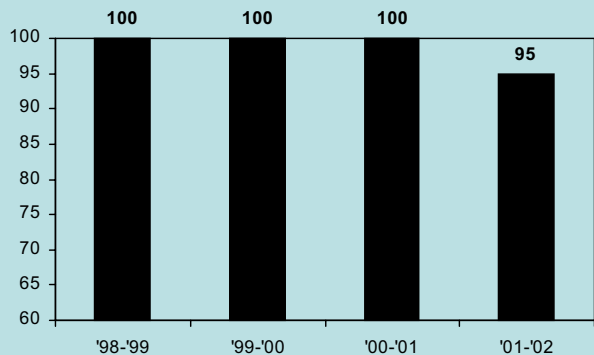
BASELINE: 98 percent

BASELINE



1998-2002 TRENDS

Of those who reported unmet benefit needs, percent who received Medicaid.



MENTAL HEALTH SERVICES WORK GROUP

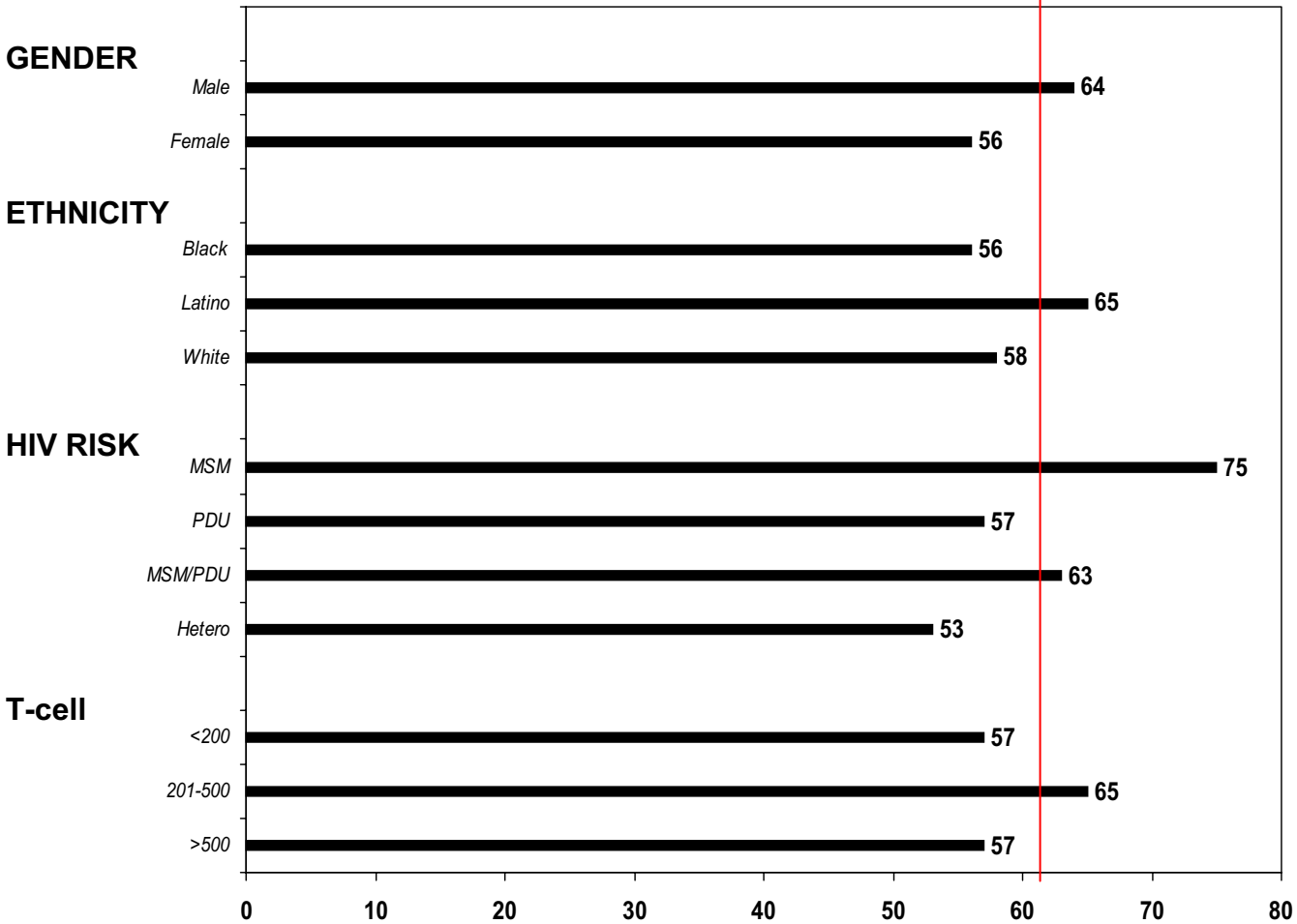
- There were no consistent trends for any of the mental health services performance measures.
- Among individuals with low mental health functioning, men who have sex with men were much more likely than individuals in other HIV risk group to report adhering to HIV medications (Objective 1B-1). Among these individuals who were also receiving mental health services, whites and those in the men who have sex with men/problem drug users HIV risk category were least likely to report adhering to HIV medications (Objective 1B-2)
- Among individuals with most need for mental health services, Latino's and those with problem drug use were most likely to report poor physical health status as well (Objectives 1C-1 and 1C-2).

Mental Health: Objective 1B-1

Persons with HIV disease engaged in mental health care and services will adhere to treatment.

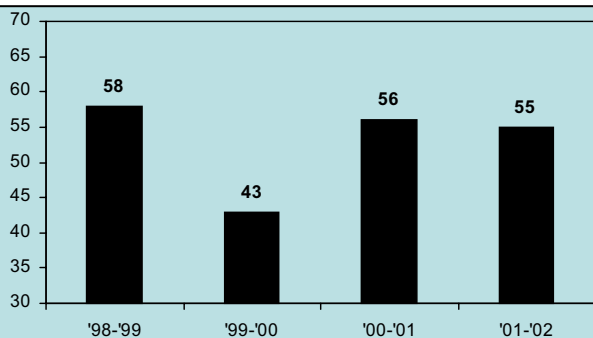
PROGRESS INDICATOR: Among those who had objective need for mental health services, those who self-reported being adherent to HIV medication plus no reported missed pills in the two days prior to interview.

BASELINE: 61 percent



1998-2002 TRENDS

Among those with objective need for mental health services, percent who reported adherence to medication.

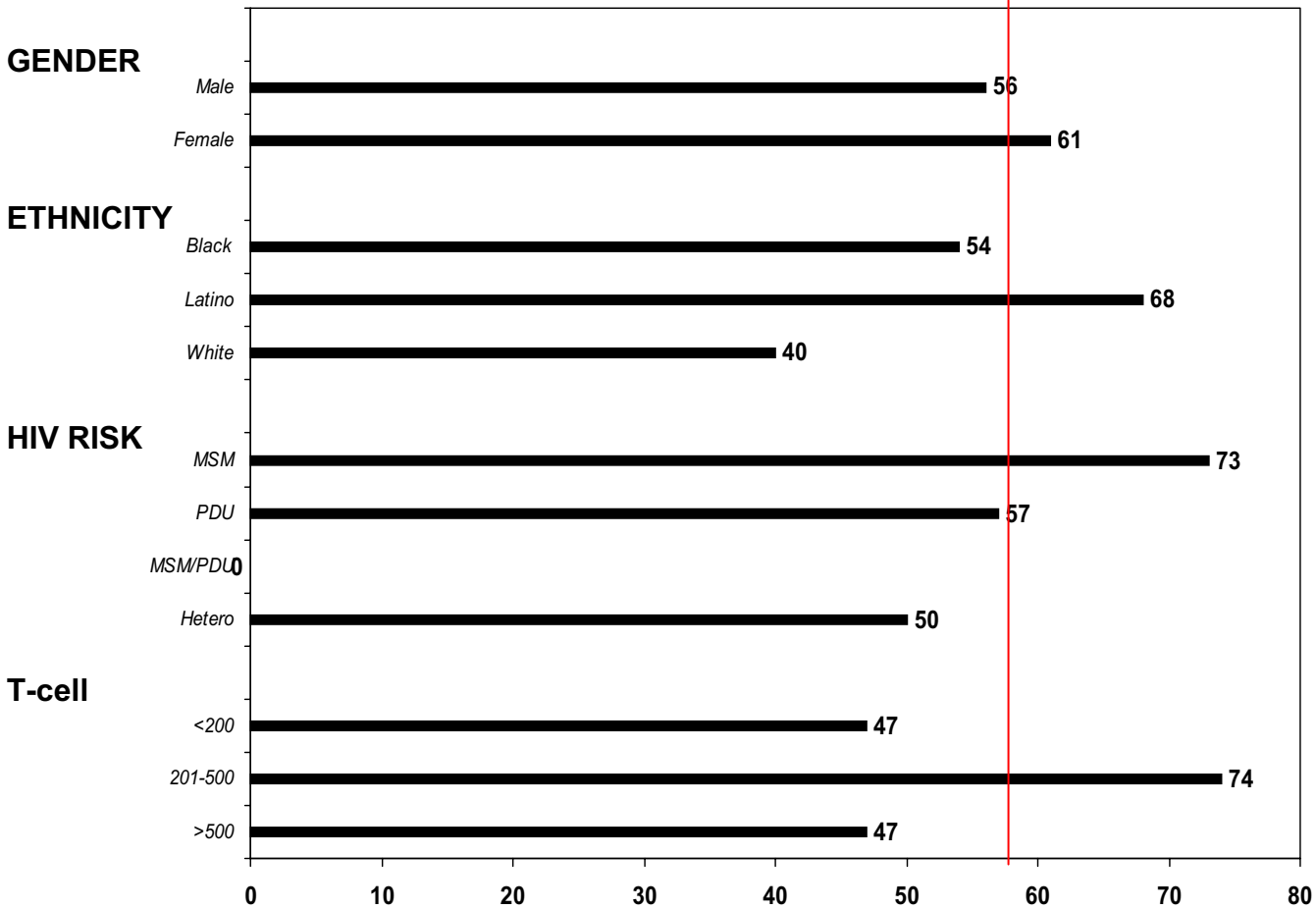


Mental Health: Objective 1B-2

Persons with HIV disease engaged in mental health care and services will adhere to treatment.

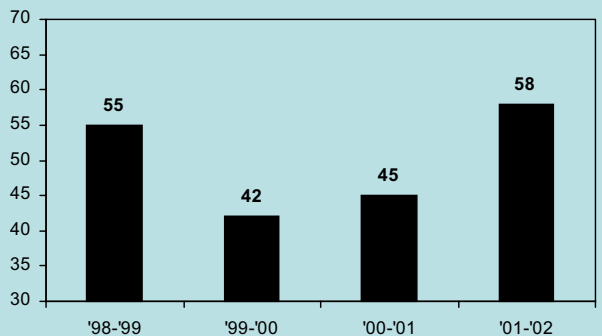
PROGRESS INDICATOR: Among those who had objective need for mental health services and reported receiving professional or supportive mental health services, those who self-reported being adherent to HIV medication plus no reported missed pills in the two days prior to interview.

BASELINE: 58 percent



1998-2002 TRENDS

Of those with objective need for mental health services who reported receiving such services, percent who reported adherence to HIV medication.

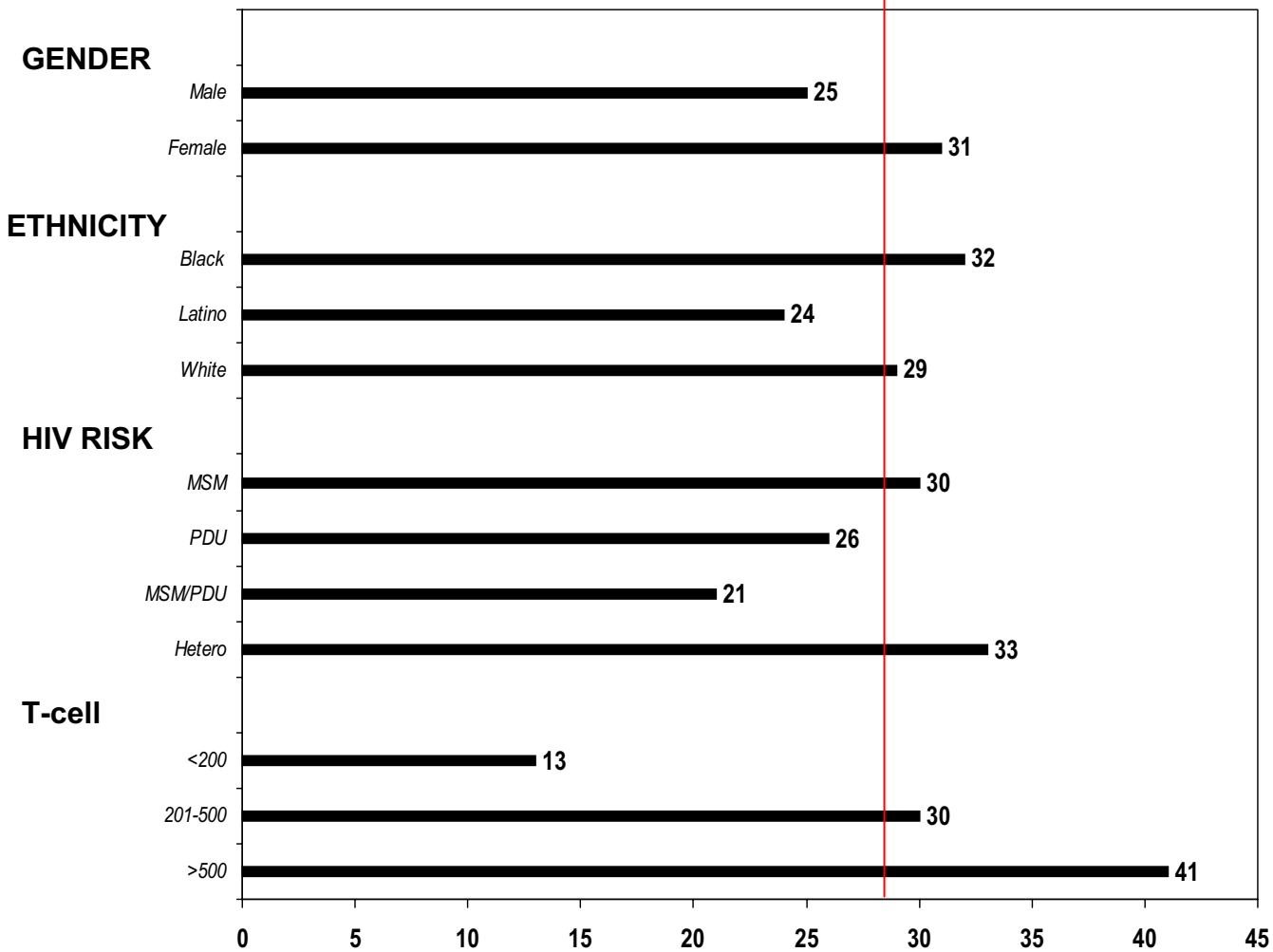


Mental Health: Objective 1C-1

Persons with HIV disease engaged in mental health care and services will have improved quality of life.

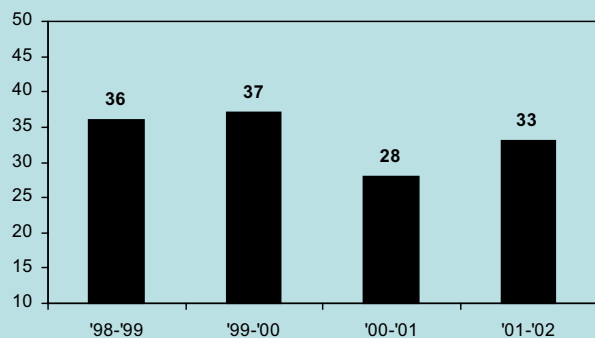
PROGRESS INDICATOR: Among those who had objective need for mental health services, their self-reported health status, as measured by PCS score.

BASELINE: 28 percent (PCS scores at or above 45)



1998-2002 TRENDS

Of those with objective need for mental health services, self-reported health status as measured by PCS score (percent scoring at or above 45).



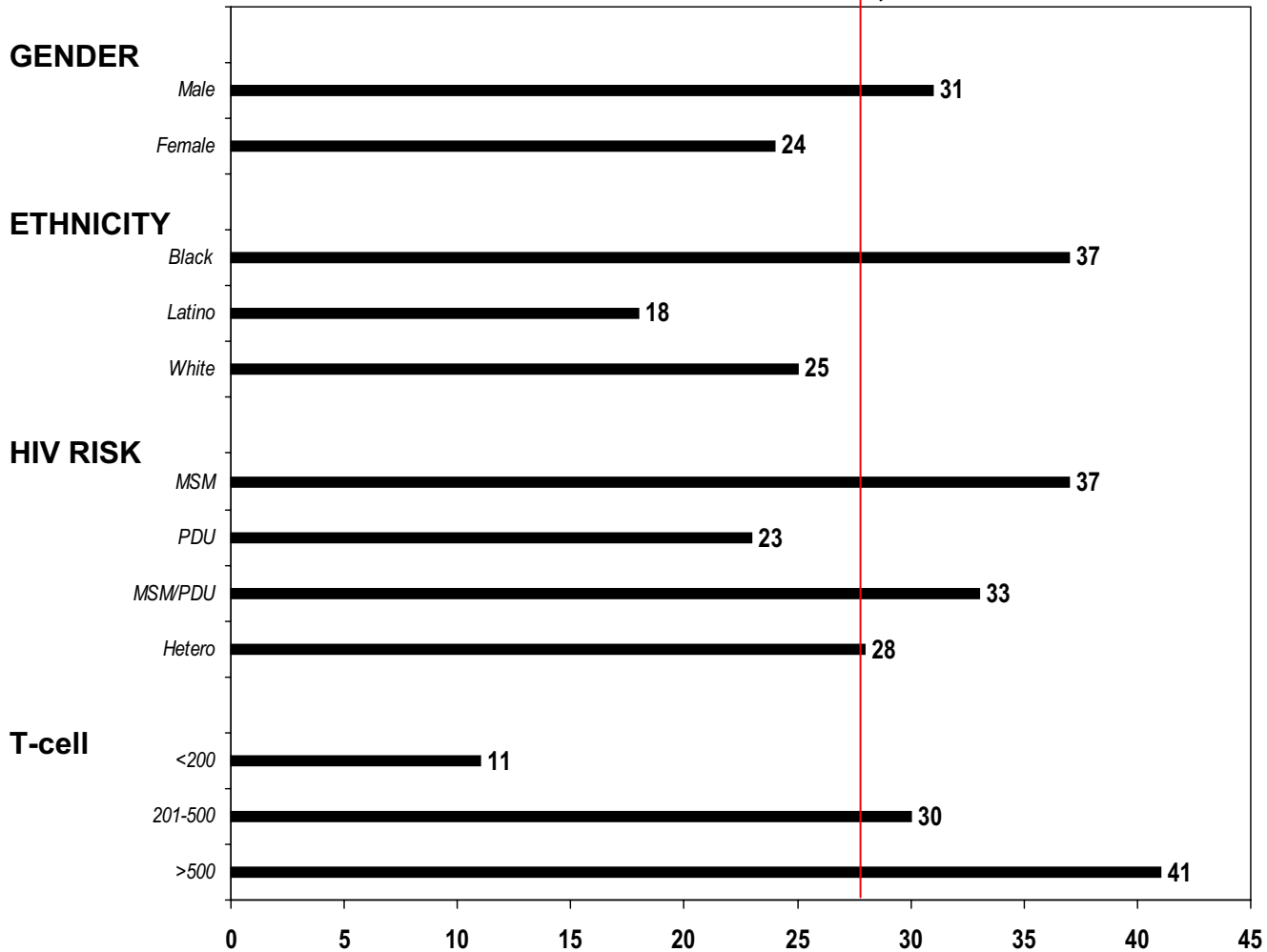
Mental Health: Objective 1C-2

Persons with HIV disease engaged in mental health care and services will have improved quality of life.

PROGRESS INDICATOR: Among those who had objective need for mental health services and reported receiving professional or supportive mental health services, their self-reported health status, as measured by PCS score.

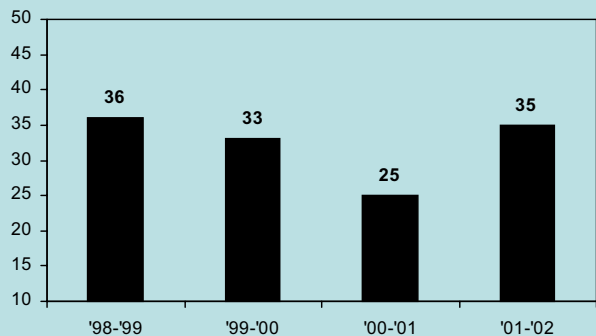
BASELINE: 28 percent (scores at or above 45)

BASELINE



1998-2002 TRENDS

Among those with objective need for mental health services who reported receiving such services, self-reported health status as PCS scores (percent at or above 45).



DATA & METHODOLOGY

Background

The purpose of the CHAIN study is to assess the impact of the full continuum of services delivered to HIV positive persons living in New York City, and to identify unmet needs for services. The interviews for this study present quantitative profiles of respondents' needs for health and human services, their encounters with health care and social service organizations, their satisfaction with services, and their current health status. The people who participated in the baseline survey are being re-interviewed at approximately annual intervals.

In 1993, the Planning and Evaluation Subcommittee of the New York HIV Health and Human Services Planning Council authorized the Medical and health Research Association of New York City, Inc. (MHRA) to develop a longitudinal study of new York City residents living with HIV. The Mailman School of Public Health at Columbia University was contracted by MHRA to conduct the ongoing survey, carry out analyses of survey data, and report its findings.

An initial cohort of 700 HIV+ individuals was recruited in 1994-1995, a refresher cohort of 268 individuals was recruited in 1998, and a new cohort of 700 HIV+ adults is presently being recruited (estimated date of completion is Summer 2003). This Baseline Report is based on the 968 individuals recruited into the original and refresher cohorts.

Sample design

One of the major goals of this study is to assemble a cohort that is broadly representative of all NYC residents living with HIV. The simplest strategy for achieving this goal, drawing a random household sample, is not feasible because persons with HIV are relatively rare in the population, and many are, for good reason, reluctant to disclose the HIV seropositive status. Therefore, to approximate the ideal sample, several sampling strategies were developed.

Agency-based random recruitment

The first strategy involved sampling clients and patients drawn from rosters of agencies providing medical and social services to persons living with HIV. To achieve a representative sample of clients, a two-step sampling procedure was followed. The first step involved identifying all health and social service agencies in New York City providing HIV services to at least twenty clients. Medical and social service agencies were independently randomly sampled within each borough and further sampled within Ryan White funded and non-Ryan White funded categories. Among approximately 400 agencies identified in 1994, 43 were sampled and agreed to be sites for participant recruitment.

The second step involved recruiting a random sample of clients from each participating agency. Random selection of clients was intended to minimize the tendency of agencies to refer their most satisfied and/or easier to reach clients. Each agency that agreed to help

recruit participants assembled a list containing anonymous identifiers for all persons living with HIV who had contact with the agency within a year of constructing the list, and also designated one of their employees to act as a liaison/coordinator between the Columbia team and the sampled individuals. In order to be eligible for the study, individuals had to be NYC residents, at least 20 years of age, and HIV+ for at least six months. The Columbia team randomly drew between 15 and 25 identifiers from each agency list. The identifiers were returned to the agency coordinators, who made initial contact with the sampled clients to explain the purpose of the study and to determine if they were willing to participate. Only then did the agency coordinator send the names, addresses and telephone numbers of consenting clients to the Columbia field staff to schedule and conduct the interviews.

Agency-based sequential enrollment

In addition to the agency-based random recruitment we employed a sequential enrollment strategy, in which all clients present at a given site during a specific time period were invited to participate in the study. Such a strategy could only be used at sites with sufficient numbers of clients (nominally 10-20 clients, as a minimum), who would be present for such a recruitment. The CHAIN research team would coordinate recruitment with an agency coordinator from the participating agency. The agency would maintain a roster of all eligible clients present during the recruitment period so that a later analysis could be conducted to determine if CHAIN recruited most (or all) eligible clients present, and if those recruited were reasonably representative of all eligible clients present.

Interview Schedule

All interviews are conducted in person by trained interviewers. The major topics covered during the interviews include: 1) initial encounter with the health care delivery system; 2) need for services; 3) access, utilization and satisfaction with health and social services; 4) sociodemographic characteristics of respondents; 5) informal caregiving from friends, family and volunteers; and 6) quality of life with respect to health status, psychological and social functioning. The interview schedule was developed based upon a listing of questions under each of these broader topics that was circulated to the Planning and Evaluation Subcommittee, NYC Department of Health, and MHRA. In particular, information on use of health and social services was obtained using questions developed for a federally-funded study of AIDS service utilization. Health status was assessed using survey questions that have well-established psychometric properties (such as the Medical Outcomes Survey scale, and indices measuring health locus of control, and self-efficacy) and which have been widely administered to HIV+ populations. The interview takes between two and three hours to complete, dependent upon issues relevant to each client's unique service needs. Between 1994 and 2002, 4159 interviews were conducted with the 968 individuals recruited in to the study, over eight rounds of data collection. Most interviews were conducted in English, although a number were conducted in Spanish.

GLOSSARY OF TERMS

AIDS Institute (AI) criteria for care—AI criteria for appropriate medical care for HIV+ persons consists of: 1) required number of medical care visits (further contingent upon T-cell count and antiretroviral use); 2) self-reported complete physical and blood work; and 3) self-reported T-cell count.

AOD—Alcohol and other drugs.

Barriers to care—Barriers to care (lack of information) were established via questions such as: “Did you ever delay or not get assistance you thought you needed” because “you didn’t know or weren’t sure where to go” for medical or social services?

Comprehensive medical care—Respondents were considered to receive comprehensive medical care if they responded “yes” to the following three questions: Is your routine medical provider someone you can go to for (1) “routine check-ups,” (2) “information or advice about a health concern” and (3) “someone you could call up 24 hours a day in case of a medical emergency?”

Cultural/language barriers to care—Established via the following questions: “Did you ever delay or not get assistance you thought you needed” because the staff “. . . Do not speak your language? . . . Are not competent to deal with your problem? . . . Are often not polite, disrespectful or insensitive to your needs?” Are you not sure that they “. . . would understand your problems?” or are “not good at listening to your problems or needs?”

Help with taking meds—Established via responses to the question: “Has anyone suggested ways to help you take your medicine on time and in the right way?”

Hetero—HIV risk group for persons who risk exposure to the virus via heterosexual contact.

MSM—Men who have sex with men.

Need for benefits—Defined by a self-reported T-cell count of less than 200 and an annual household income of less than \$10,000.

Objective need for mental health services—Established by a score of less than 37.0 on the Mental Health Component Summary score of the SF-36, developed by the MOS.

PCS score—Physical Component Summary score of the SF-36, developed by the MOS. Scores of 45 and above are considered “high.”

PDU—Problem drug users.

Professional mental health services—Mental health services provided by a psychiatrist or psychologist.

Supportive mental health services—Mental health services such as counseling provided by a case manager, clergy, etc.

Unstable housing—Any episode of living in the street, a shelter, a single-room occupancy, or doubled up with a friend or relative in past 6 months.