




The New York City CHAIN Study

Presentation to the HIV Planning Council

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Research Team

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- Technical Review Team -- MHRA, NYC DOHMH, Office of AIDS Policy, HIV Planning Council
 - Mary Ann Chiasson, DrPH, MHRA (chair); JoAnn Hilger, NYC DOHMH; Robert Cordero, HIV Planning Council; Susan Forlenza, MD, MPH, NYC DOHMH, Julie Lehane, PhD, Westchester County DOH; Jennifer Nelson, MHRA, and Fatima Prioleau, PWA Advisory Group

Using CHAIN As a Planning Tool

- Basic CHAIN background
- Applying CHAIN to the Strategic Plan
- Using CHAIN to define service gaps & unmet needs
- Illustrating service utilization
- Mapping services, utilization, and need
- Strengths & limitations of CHAIN data

Basic CHAIN Background

- Constellation of studies
- Evaluation objectives
- Data & Methods
- Representativeness
- Collecting data & topics covered

CHAIN studies

Ancillary Service, 1999

Social Comorbidities, 2000

Ryan White Impact, 2001

Personnel Needs

1995 - 1996

Adolescent Study

1995

Client Study – Adults

1994-2002

Tri-County Client
Study

2002

The Unconnected

1995 & 1998

Delayers to Care

2002

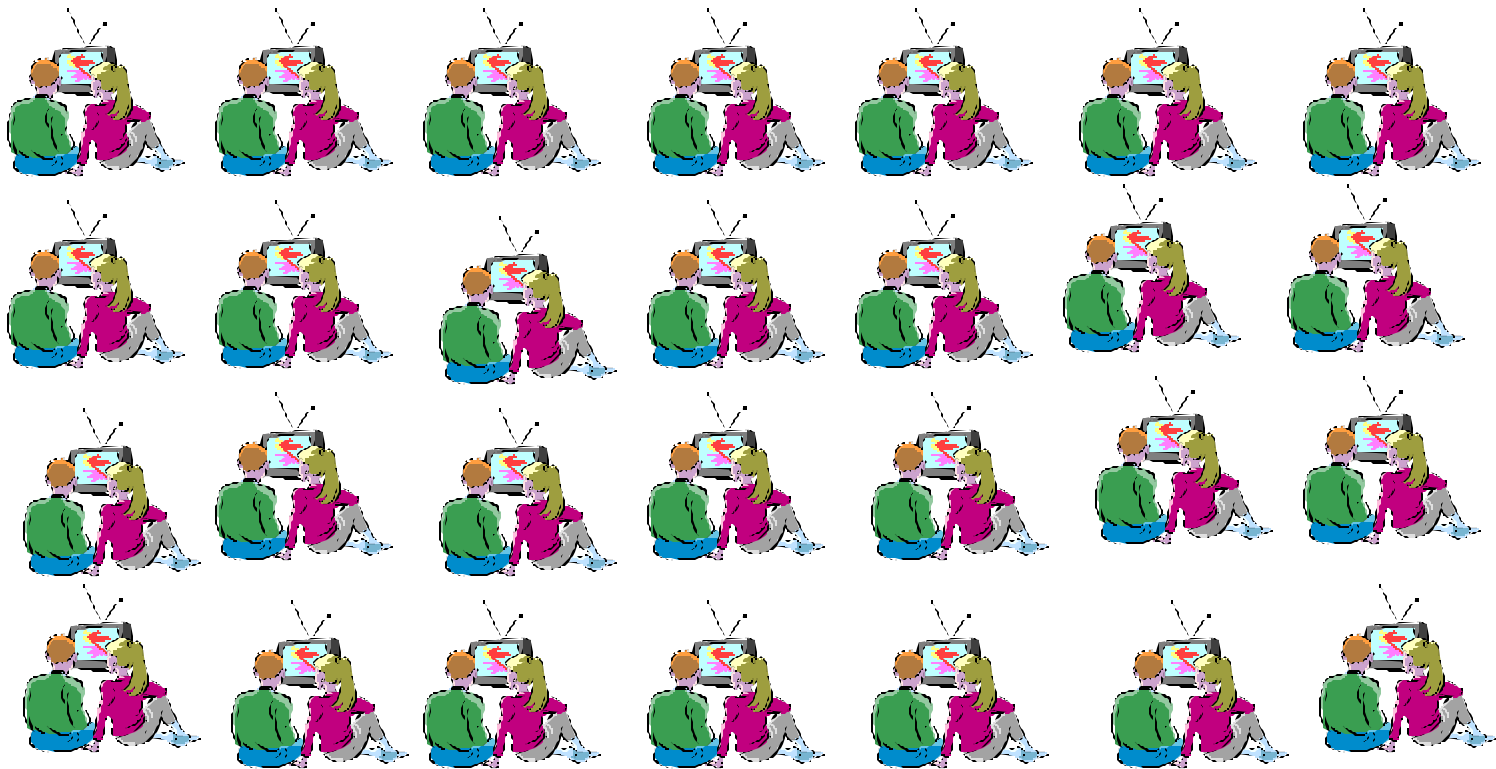
Evaluation Objectives

- To recruit and maintain a representative cohort of HIV positive adults in the system of care in NYC
- To assess the system of HIV care – both health and social services – from the perspective of people living with HIV
- To report on unmet needs, service utilization trends, and outcomes to the Planning Council & its Work Groups

CHAIN Data & Methodology

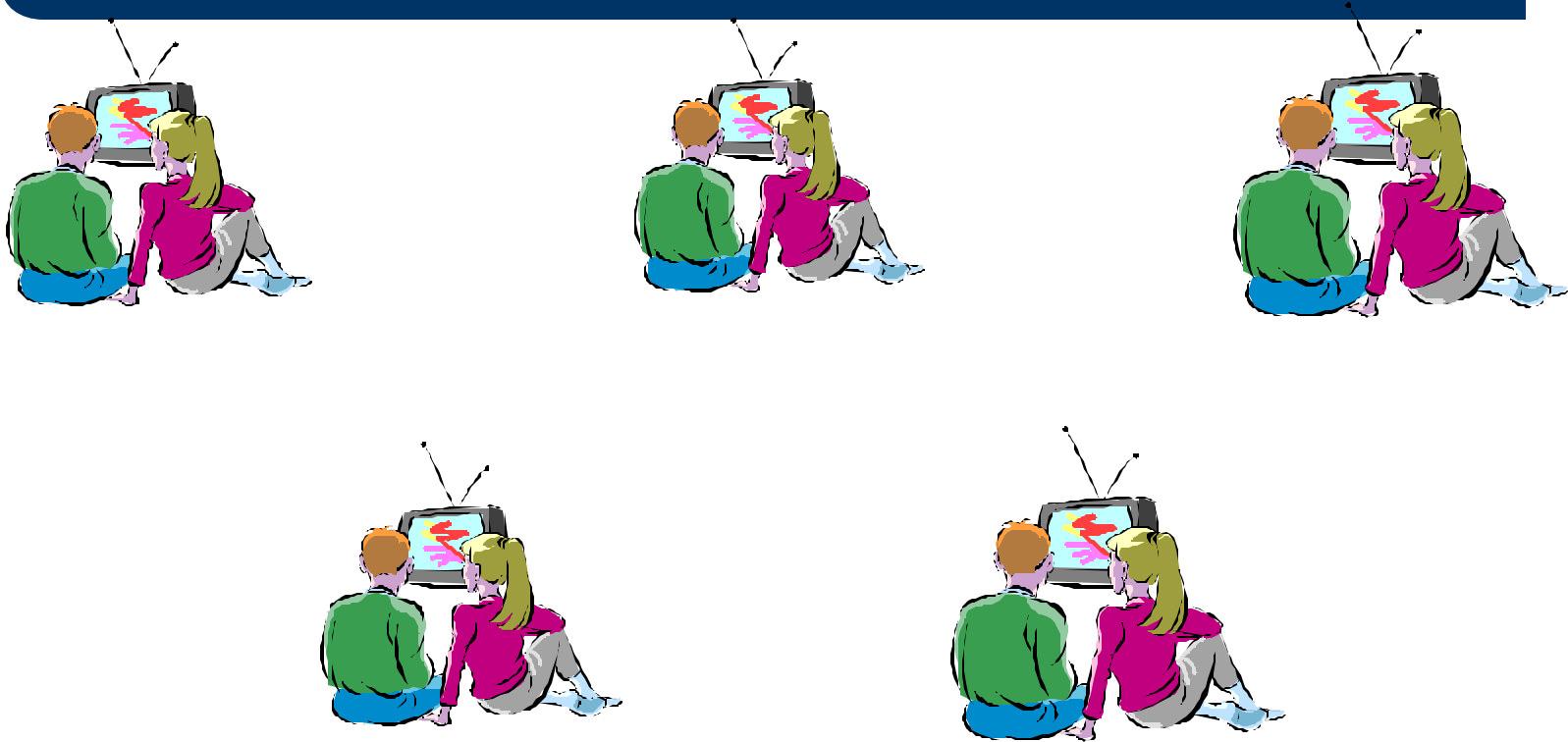
- Multi-stage stratified sampling
- Initial recruitment 1994-95, n=700
- Refresher cohort 1998, n=268
- 8 waves of interviewing of Cohort I
- Cohort II currently being enrolled, 2002-2003, projected n = 700

Nielson ratings: A Probability Sample



102 Million American Households

Nielsen ratings: A Probability Sample



5,000 Nielsen households

The CHAIN Cohort is a Probability Sample

60,000 –
75,000 HIV+
adults in care
in NYC

The CHAIN Cohort is a Probability Sample

60,000 –
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CHAIN = 968 people

CHAIN Sampling, A 2-Step Process

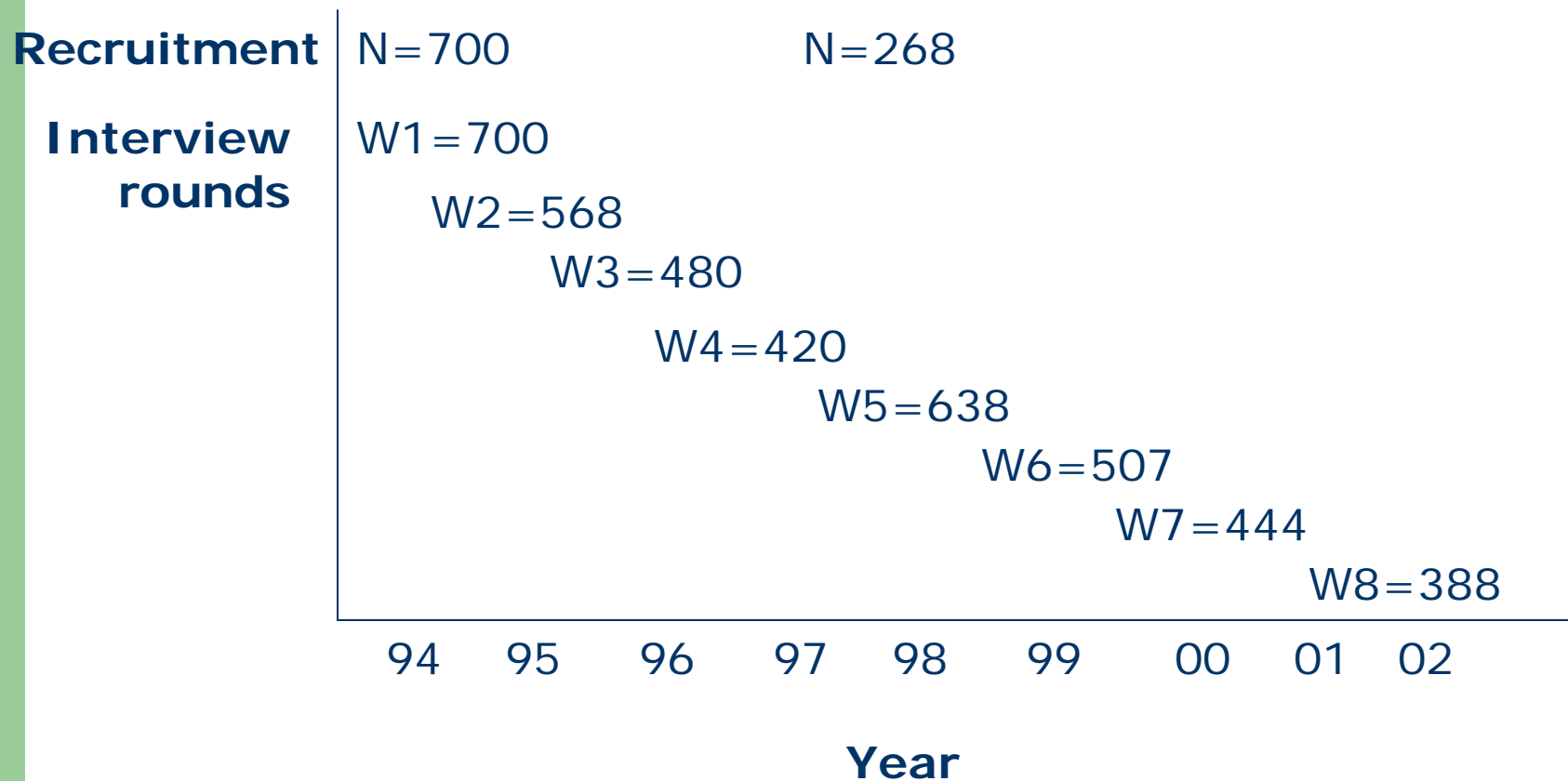
- 1st step: enumerate all health and social service agencies serving HIV clients (in 1994, n=~400)
 - Primary Medical vs Social Service
 - Borough
 - RW Funding
- 2nd step: randomly sample agencies by above strata (n=43)
- 3rd step: recruit clients
 - Random list recruitment
 - Sequential enrollment

Comparison of Epidemiological Data with CHAIN Data

	Cumulative AIDS Cases, NYC†		CHAIN Cohort I
		1995-2000	1994-2002
	n	40,760	968
MALE		29,046	579
<i>Non-Hispanic White</i>		21%	21%
<i>Non-Hispanic Black</i>		43%	48%
<i>Hispanic</i>		34%	30%
<i>Other</i>		2%	1%
FEMALE		11,714	389
<i>Non-Hispanic White</i>		9%	6%
<i>Non-Hispanic Black</i>		57%	63%
<i>Hispanic</i>		33%	31%
<i>Other</i>		1%	<1%

† NYC DOH HIV/ AIDS Surveillance Program, “AIDS Surveillance Update, 4th Quarter 2000”

CHAIN Chronology



Collecting Data

- Respondents interviewed annually
- Most often in their homes
- Community-based interviewing team
- \$25 incentive (MetroCard, tokens, or gift certificate) for every interview + referral resource

Topics Covered

- Current health status
- Family, housing, work, resources
- Outlook on life
- Risk behaviors – sex & drugs
- History and use of medical services
- History and use of social services
- Needs, satisfaction, barriers

Applying CHAIN to the Strategic Plan

- NY EMA Comprehensive Strategic Plan, 2002-2005
- Based on approx. 36 meetings with Work Groups, PWA Advisory Group, and key committees
- Work Groups identified 19 goals and 40 objectives
- CHAIN data identified by Work Groups and consultant as performance measures for 21 of 40 objectives
- Strategic Plan Progress Indicators: Baseline Report, a 2003 CHAIN report

Illustration: Strategic Plan & CHAIN

- Health Services Goal 1: “Ensure that people with HIV achieve and maintain optimal health and well being”

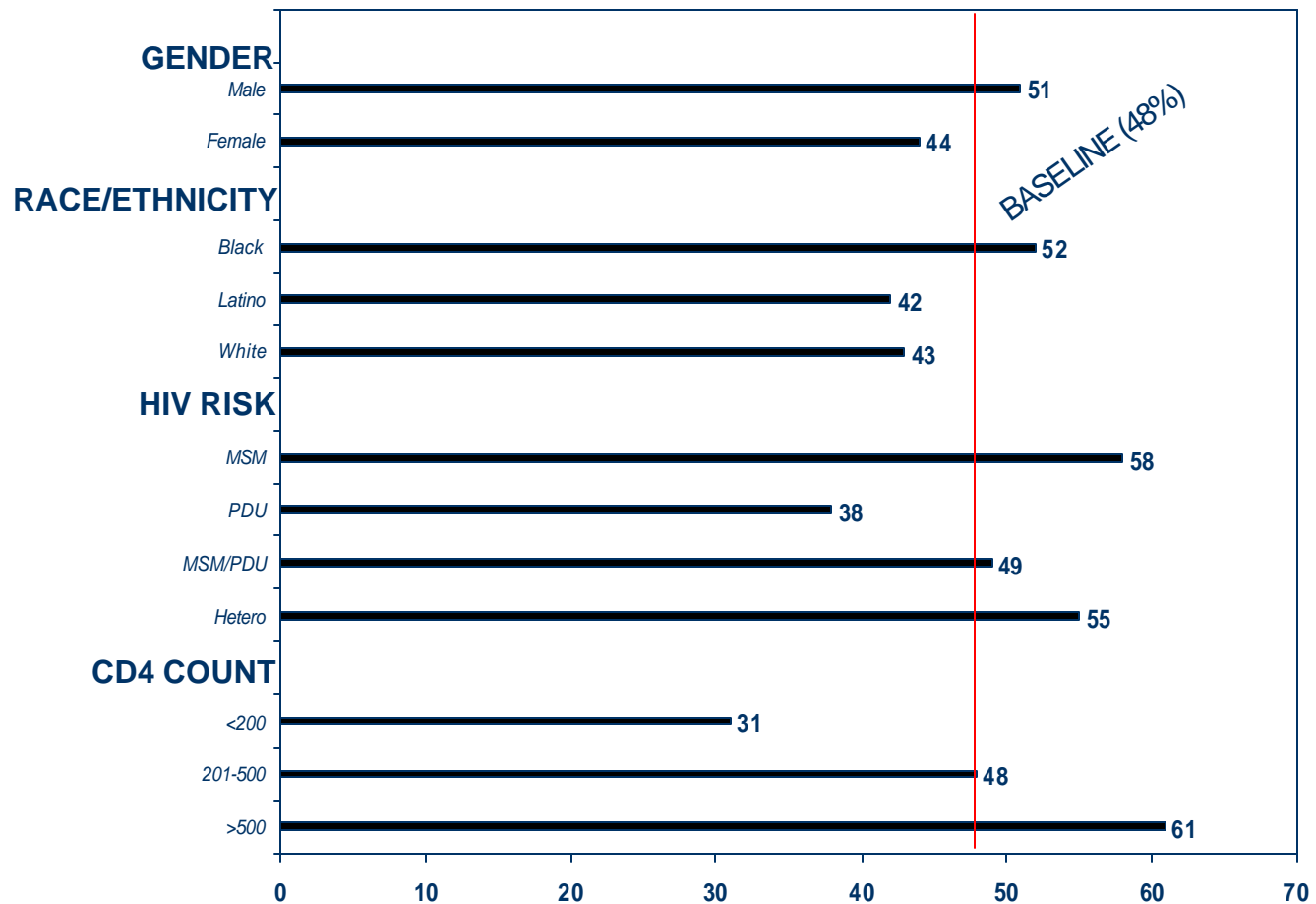
Illustration: Strategic Plan & CHAIN

- Health Services Goal 1: “Ensure that people with HIV achieve and maintain optimal health and well being”
- Objective 1A: “Persons with HIV disease engaged in health care services will have improved survival and health outcomes”

Illustration: Strategic Plan & CHAIN

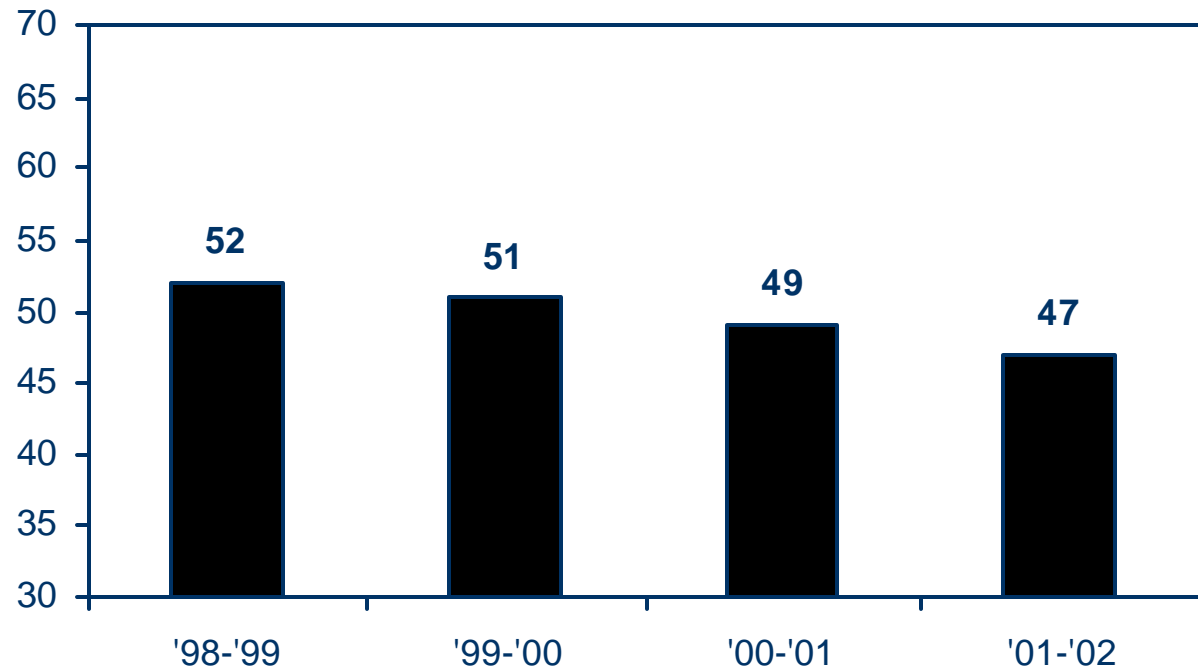
- Health Services Goal 1: “Ensure that people with HIV achieve and maintain optimal health and well being”
- Objective 1A: “Persons with HIV disease engaged in health care services will have improved survival and health outcomes”
- CHAIN indicator: Self-reported health status, as measured by standardized health function scale

Percent of CHAIN Cohort with Physical Component Score > 45 (“good health”)



1998 – 2002 Trends in Health Status

Percent of the CHAIN Cohort with a Physical Component Score > 45 (“good health”)



Note: Missing values have been imputed for cases lost to follow-up

Identifying Service Gaps

- “Subjective” expression of need (demand)
- “Objective” expression of need
- Report of service to address need
- Resolution of need – improvement, or no change/or problem has gotten worse

Illustration: “Objective” AOD Service Gap

		Former AOD Users	Current AOD Users	Former + Current
A	Total	260	81	341
B	# NOT in therapeutic or self-help treatment	200	58	258
C	“Objective” service gap (B / A)	77%	72%	76%

Data: CHAIN Wave 8, n = 388 (2001-2002)

Illustration: “Subjective” AOD Service Gap

		Former AOD Users	Current AOD Users	Former + Current
A	Total	260	81	341
B	# who express an interest in AOD treatment	119	45	164
C	Of those, # NOT in therapeutic or self-help treatment	73	24	97
D	“Subjective” service gap (C / B), as unmet demand	61%	53%	59%

Data: CHAIN Wave 8, n = 388 (2001-2002)

Illustration: Housing Service Gaps

A	Total	388
B	# who expressed a need for housing services	113
C	Of those, # who received a housing service	45
D	Of those, # whose need for housing services was NOT resolved	21
E	Service gap: % with an expressed need who did not receive service = $(B-C)/B$	60%
F	Unmet need: % of those who expressed a housing need for whom need was NOT resolved $(D + (B-C)/B)$	79%

Data: CHAIN Wave 8, n = 388 (2001-2002)

Service Utilization & Health Behavior Trends

- CHAIN can illustrate service utilization trends alongside client need or clinical markers
- Trend data may illustrate increasing or decreasing patterns of needs, services, or specific health behaviors

Illustration 1: Health Trends

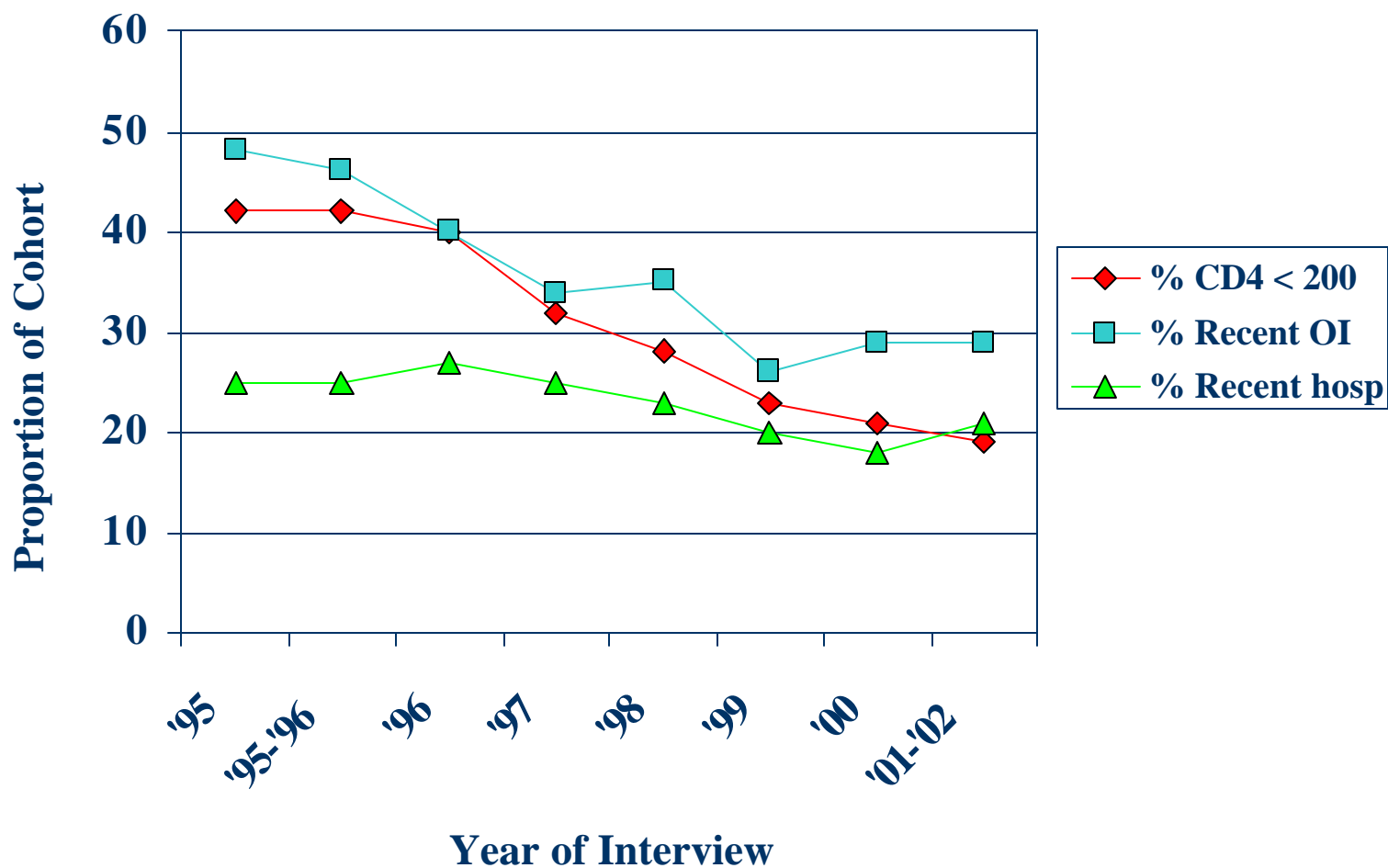


Illustration 2: Mental Health Trends

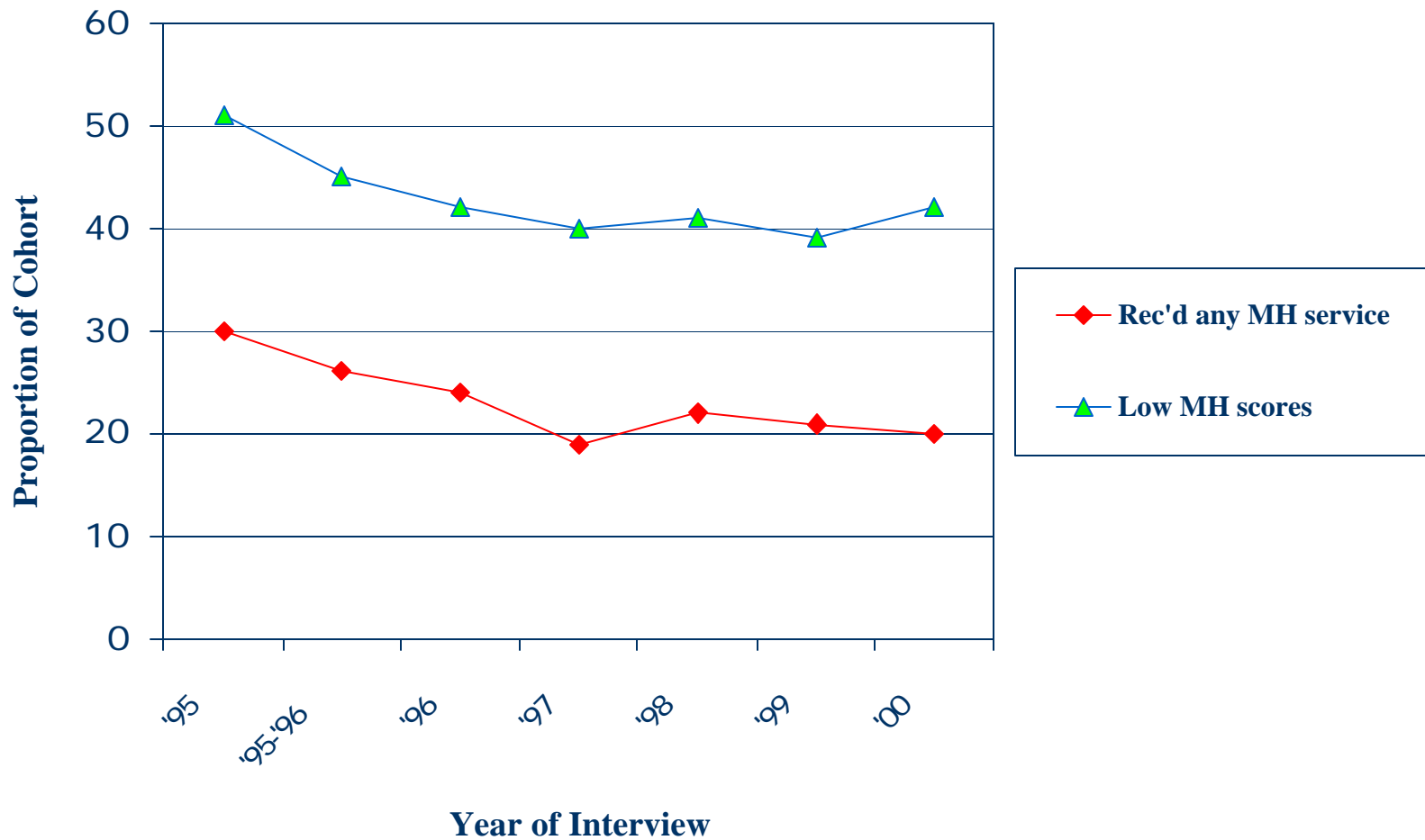
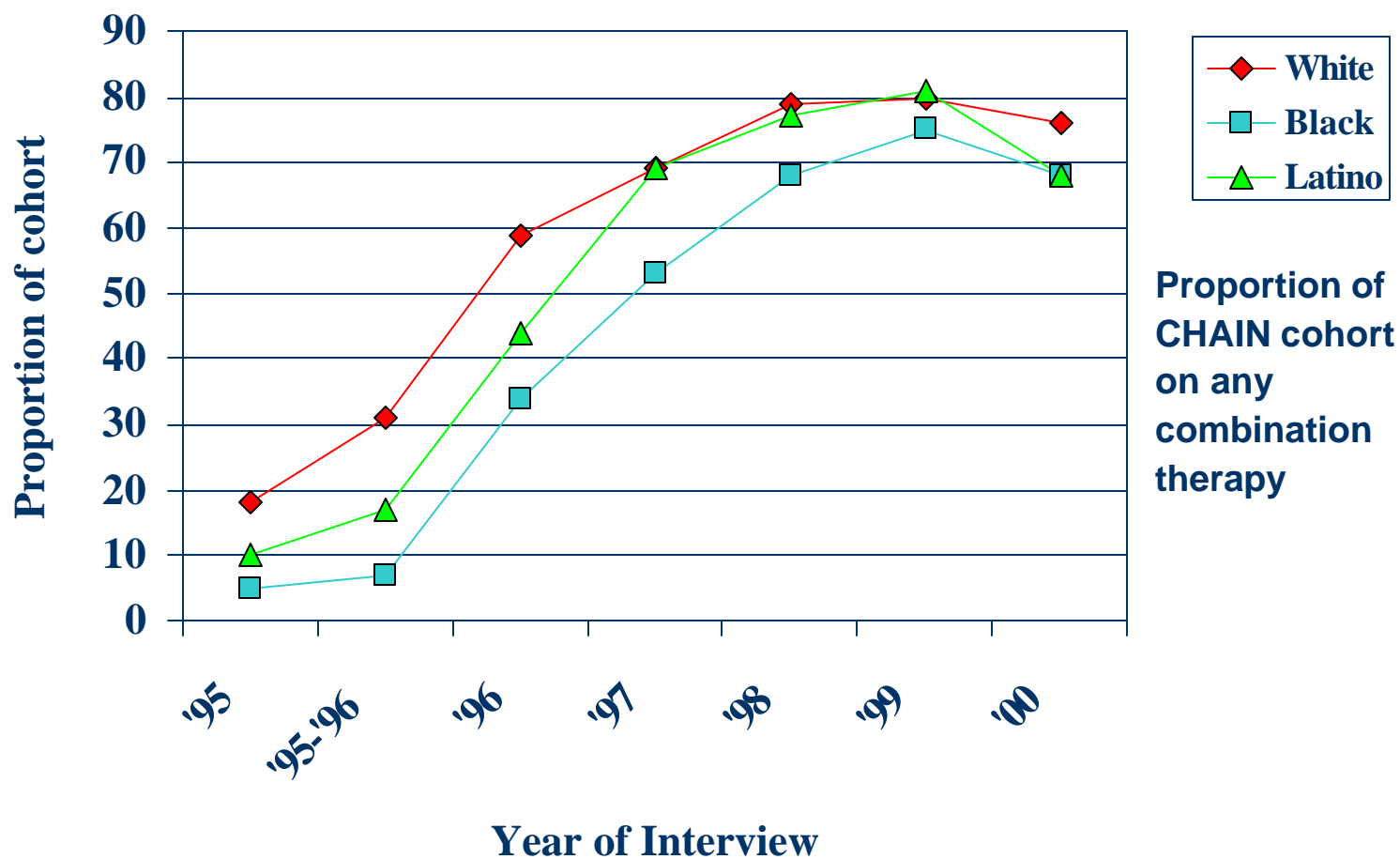


Illustration 3: Antiretroviral Trends

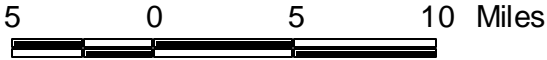
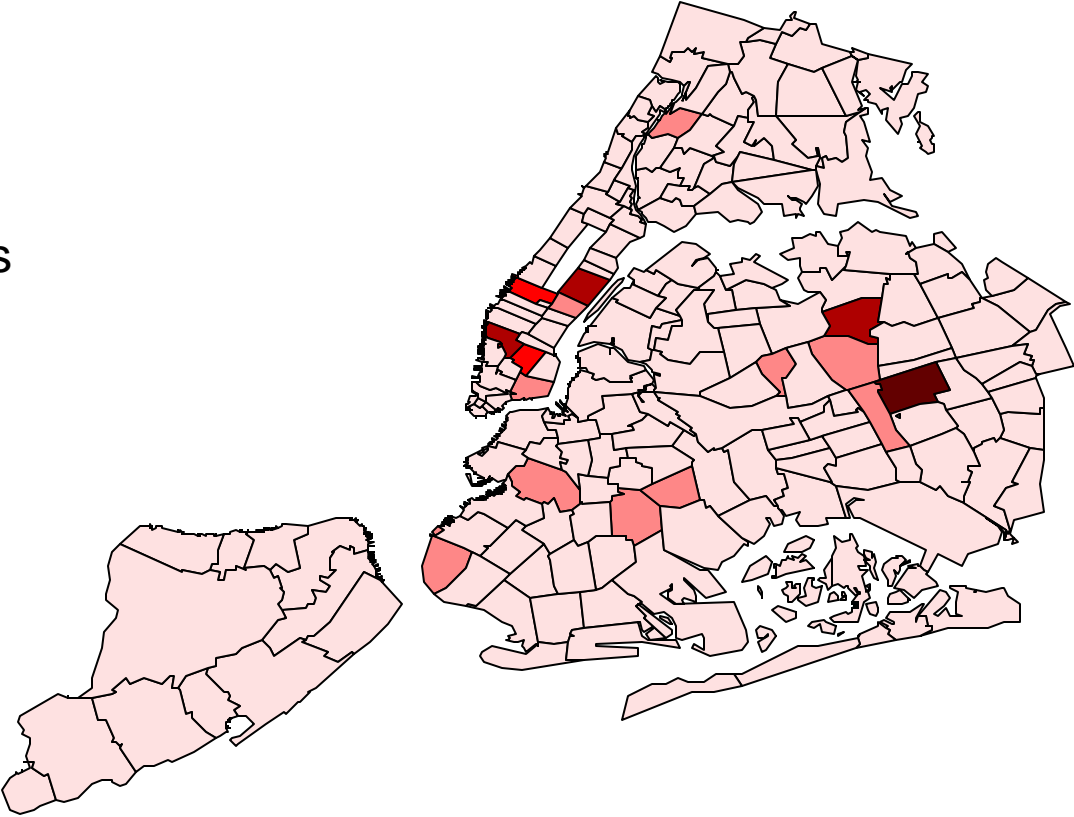
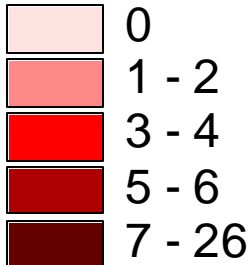


CHAIN Mapping

- PLWA prevalence, by zip code or UHF area
- Agencies, by RWCA funding and service category, geocoded to address
- CHAIN cohort service utilization, by type of service

Queens CHAIN Residents (n=68) Distribution of Current Medical Providers

Queens Medical Providers



Manhattan CHAIN Residents (n=169) Distribution of Current Medical Providers

Manhattan Medical Providers

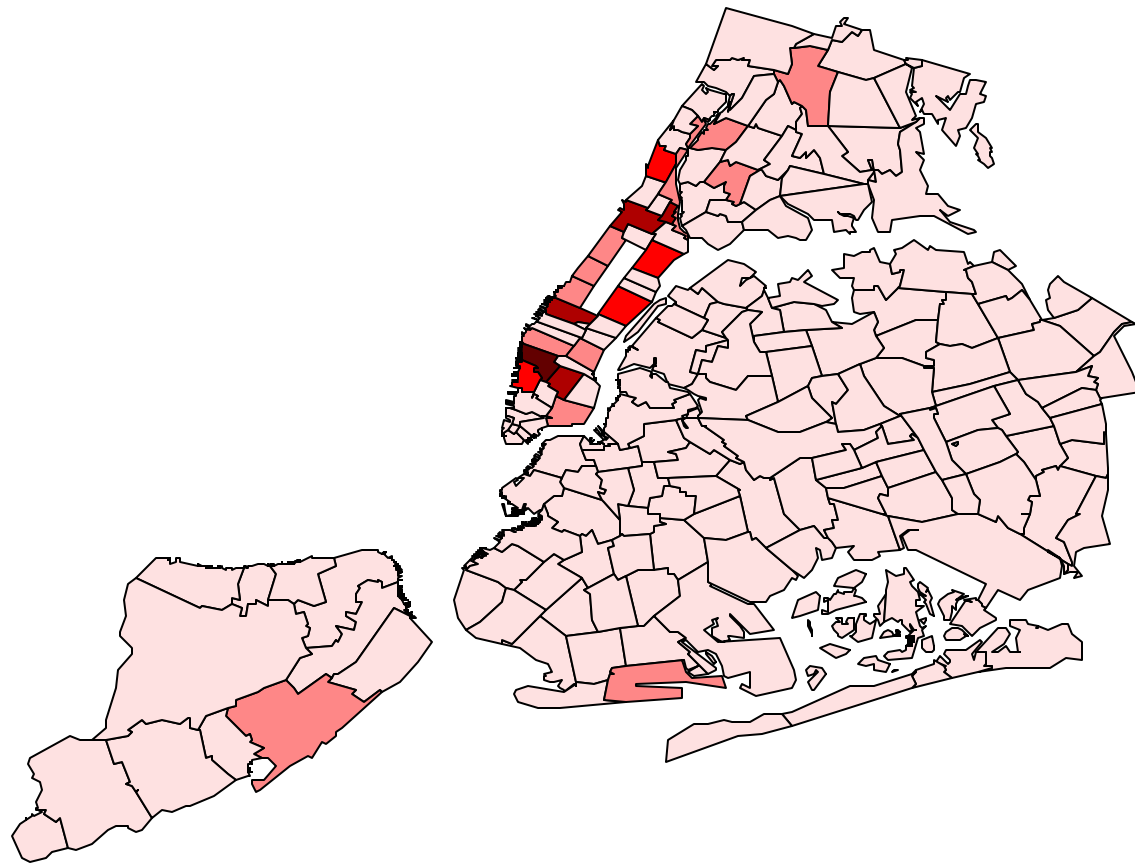
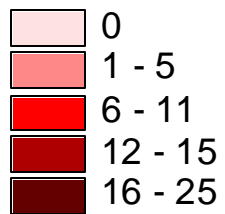
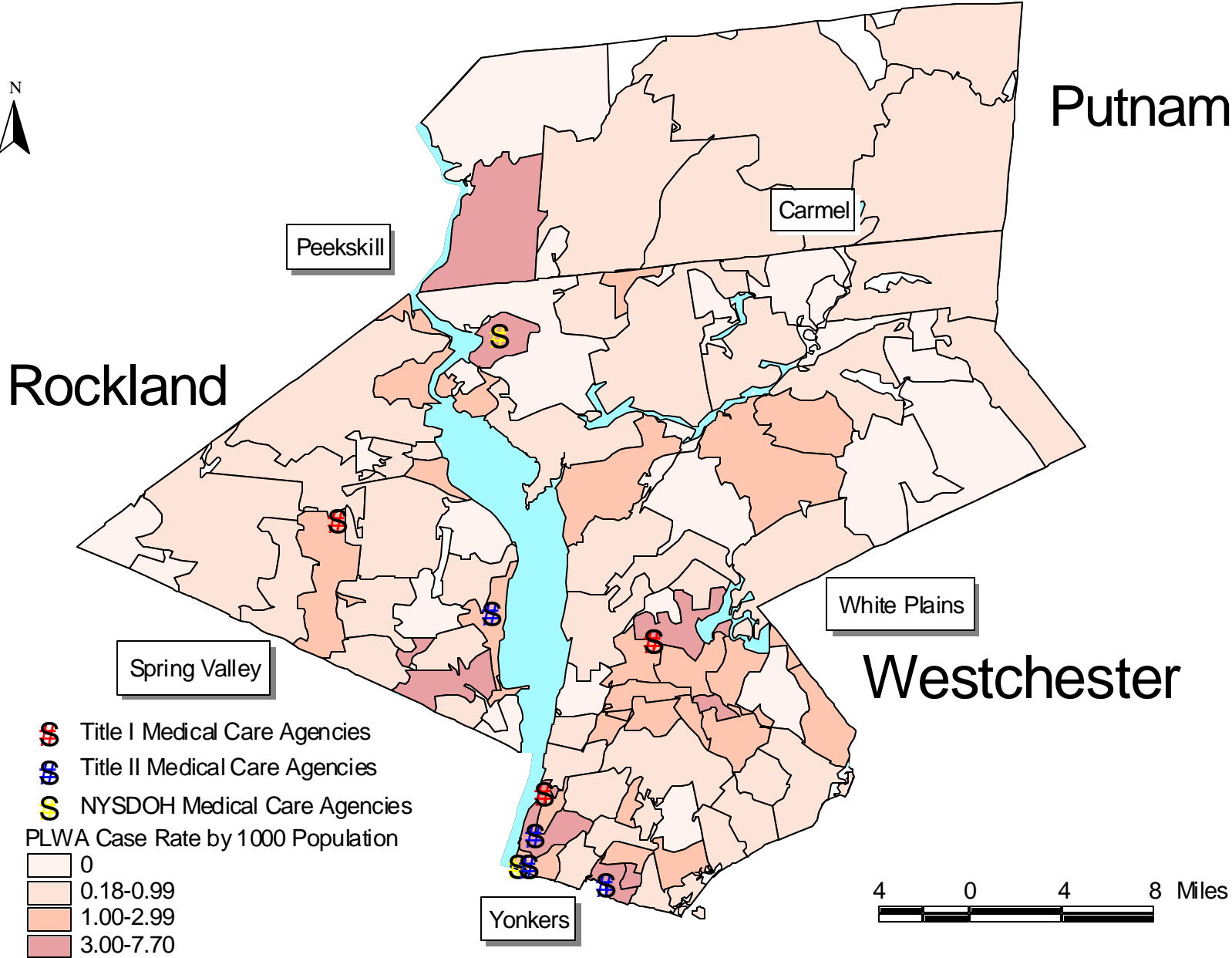


Figure 2. Distribution of Ryan White Title I & II and NYSDOH medical care agencies in Tri-County region



MH1. Mental Health Service Need People and RW Funded MH SVC Agency in New York City

	Rw funded Medical Agency	CHAIN Cohort		
		(N)	Need	No Need
	69	(532)	27%	73%
Manhattan	39	(137)	28%	72%
Bronx	8	(182)	29%	71%
Brooklyn	14	(113)	27%	73%
Queens	6	(57)	30%	70%
Staten Island	2	(43)	16%	84%



- MH svc needy (143)
- ⌋ MH-RW (69)
- Subway Line

Strengths of CHAIN as Planning Tool

- Broad overview of NYC system from perspective of PLWHA in different settings and geographic locations
- Ability to respond rapidly to emerging policy and planning issues
- Capacity to track needs, services, gaps, and client outcomes
- Can identify disparities among major segments of PLWHA population

Limitations of CHAIN as Planning Tool

- Does not include independent biologic measures, such as resistance-testing
- Does not collect cost information
- Is not appropriate for identifying unique needs or issues of smaller subgroups of HIV+ population
- Does not include HIV+ who are unaware
- Does not include HIV+ in private medical care with no other service needs

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