COMMUNITY HEALTH ADVISORY & INFORMATION NETWORK (CHAIN) PROJECT

Needs Assessment Committee

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HIV Service Planning Questions

What services do HIV+ persons need?

Where do they go for care?

What are their unmet needs/ service gaps?

What populations are underserved?

What works well, what doesn't work?

What are the barriers and access issues?

Where should we put our money?

The CHAIN Project

Community Health Advisory & Information Network(CHAIN)

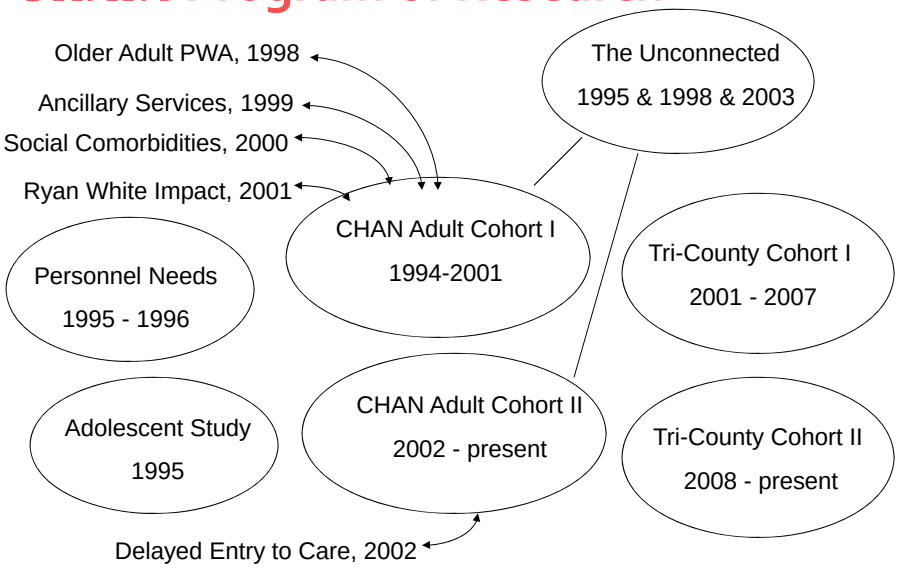
Project Goals:

- To provide a profile of PLWH/A in New York City //and the Tri-County Region
- To assess the system of HIV care – both health and social services – *from the perspective of* people living with HIV/AIDS
- To report on unmet needs, service utilization trends, and outcomes to the Planning Council and its Committees
- Make research results available to the wider provider, consumer, and other stakeholder communities

History of CHAIN

- Planning Council initiative in 1993 as one of the Council's evaluation resources
- Contract with Columbia University Public Health
- CHAIN has recruited 4 cohorts of PLWH
  - NYC I (1994-2002, n=968)
  - NYC II (2002-present, n=1015)
  - Tri-County I (2001-2007, n=482)
  - Tri-County II (2008-2013, n=234)
- A Technical Review Team oversees CHAIN
  - includes representatives of the Planning Council, its PWA Advisory Group, MHRA/ Public Health Solutions, NYCDOHMH and (xx) Office of HIV/AIDS Planning oversees CHAIN

CHAIN Program of Research



Steps in a collaborative process

Interactive collaboration with multiple stakeholders

Providers, PLWH, Planning Council & Committees, RW Grantee (NYC DOHMH), Public Health Solutions, Westchester DOH

Steps in the process:

- Define study questions
- Develop a research strategy
- Design data collection tools
- Develop research infrastructure
- Implement strategy
- Analyze & report on research findings
- Define new study questions
- Re-evaluate strategy and tools

Selecting CHAIN Participants

Designed to enroll representative samples

- **1st step: random selection of service sites from listing of all agencies serving HIV clients**
  - Medical and Social Service providers (excluding private md offices)
  - All Boroughs (or Counties)
  - RW Funding vs. no RW
- **2nd step: agency staff help with random selection of clients**
  - Random selection from client rosters (age 20+)
  - Sequential enrollment
- **Separate effort to locate and enroll PWH out of care**
  - PLWH Network sampling, direct outreach

Collect Information by Speaking with PLWH

- Comprehensive in-person 2hr+ interview
- Follow-up interviews approx. yearly
- Interviews in homes or agency settings
- Community-based interviewing team, many HIV+
- $35 incentive for every interview + referral resource
- Strong community support with 80% - 90% follow-up interview completion rate
- Over 8,000 over-time interviews with 2699 PLWH

Topics Covered

- Current health & mental health status
- Sociodemographic background
- Family life, housing, work, economic resources
- Sexual behaviors
- Outlook on life, stress, stigma
- Substance use behaviors
- Testing and entry into care experiences
- History of medical and social services
- Utilization of medical and social services
- Medication use and adherence
- Service needs, satisfaction with services, barriers
- Social networks, social support
- Quality of life

Commitment to include 'harder to reach"

CHAIN committed to including voices of those often not included or under represented in research

- Homeless/ transient living arrangements
- Multiple competing life challenges
- Mental health and/or substance use challenges
- In and out of medical care
- Distrust medical providers/ government agencies/ academic researchers
- No easy phone contact

Data collection challenges

- Address change since last interview =50%; same phone <40%
- Last 50 cases = 200+ days to locate and complete follow-up
- Understanding of service need, what predicts dropping out of care etc different results if include or exclude last 50 cases

Value of CHAIN

- **Population-based probability sample**
  - Patterns proportions we see in the sample can be used as estimates for the broader HIV+ population
  - Not just PLWH in care or receiving specific type of service
  - Study sample comparable to RW client base/ target population
- **Collects broad range of data - flexible to address emerging issues**
- **Cohort study - follow up with same persons**
  - Over time data can show changes in needs as well as effects of services received
  - Can also show effects of system-wide interventions and funding and other policy changes
- **Learn how need and services experienced by patients and clients**

Analyze & Report

- Work with Council committees & staff to define topics
- Consult with stakeholders
  - What emerging issues should be investigated?
  - What subgroup comparisons?
- Prepare draft of reports and get feedback
- Disseminate final reports
- Over 200 reports freely available (www. nyhiv.org)
- Multiple presentations to Council, committees, community groups (monthly or more often)
- Rapid response brief reports in response to Council or NA requests

Types of Analyses

Descriptive

-- rates, percentages, mapping, trends over time

Analytical

-- Are there group differences? (beyond demographics)

-- Do certain models of care, interventions, or policies make a difference?

Multivariate analyses – considering the effects of many factors taken together

-- Can include individual (e.g. mental health), situational (e.g. currently homeless), service provider (e.g. medical home) characteristics

Assessing the System of Care

Conduct studies to examine:

- Medical care, health, mental health, QOL outcomes for PLWH
- Trend data – tracking change over time
- Individual factors associated with outcomes
- Service utilization associated with outcomes
- Systemic factors associated with outcomes

Key resource for needs assessment – can show service system strengths and weaknesses

Example: Understanding Service Gaps

- The difference between the "need" for service, and the receipt of service
- Need may be "subjective," in that client explicitly wants service (AKA "demand")

  --Ex: "In the last 6 months, have you had a problem or needed assistance with housing?"
- Need may be "objective," in that client's circumstances suggest a need for a service, even if client doesn't demand it

  -- Ex: Client has had at least one episode of homelessness, being doubled up, or being unstably housed in past 6 mo.

Example: Alcohol or Drug Treatment

Who Needs the Service?

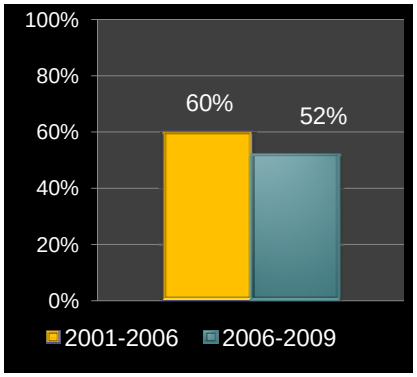
1. **During past year used cocaine, crack or heroin,**
2. **During past 6 months heavy or problem drinking, or**
3. **Participant reported receiving drug or alcohol treatment /further treatment was important to him/her**

Measure of Adequate Utilization

In last 6 months received any form of treatment for alcohol or drug use, including AA/NA

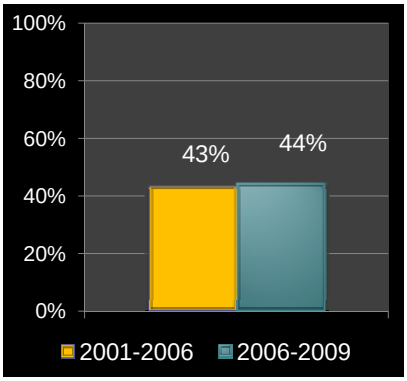
Trends in Alcohol or Drug Treatment

Need for Service



Among PLWH interviewed 2006-2009, 52% indicated need for AOD treatment/ further treatment or services

Utilization of Service



Among PLWH interviewed 2006-2009, among those with 'need' for service 44% received any AOD treatment or services (56% did not)

Example: Service Need Permanent Housing

	Need	Adequate Utilization
HOUSING		
Permanent Housing	(1) Homeless or unstably housed past six months OR (2) facing eviction or urgent need to move without resources to secure adequate housing past six months OR (3) received housing assistance past six months that resulted in resolution of need for permanent housing or great deal progress toward resolution	Received housing assistance past six months that resulted in resolution of need for permanent housing or great deal of progress toward resolution

29% of CHAIN Sample Needed Permanent Housing

Of those with need, **30%** got needs met within the past six months

SOME CHAIN REPORTS ON HOUSING…

1995- Summary Tables for Baseline Client Survey
1995 -The Adolescent HIV Study: Needs, Utilization and Barriers for Care
1995 - The "Unconnected" - Service Needs of HIV+Persons Outside of Care
1996 - Housing & HIV/AIDS in New York City
1997 - Continuity and Change in Housing Problems & Need for Housing Services
1998 - Top Client Indentified Unmet Needs for Medical and Social Services
1999 - The Unconnected Revisited: PLWHA Outside the Services System
2000 - Housing Services and Housing Stability Among Persons with HIV/AIDS
2000 - The Impact of Ancillary Services on Entry & Retention to HIV Medical Care
2001 - Housing and Health Care among Persons Living with HIV/AIDS
2001 - Housing Status and Health Outcomes among Person Living with HIV/AIDS
2003 - Patterns of Sexual Behaviors and Sexual Risk among HIV+People in NYC
2003 - Delayed Entry into HIV Care
2004 - Service Gaps and Utilization in The Continuum of Care in New York City
2005 - Delayers, Drop-outs, The Unconnected and Unmet Needs
2006 - Housing Status and Entry into HIV Medical Care
2007- Housing Need, Housing Assistance, and Connection to HIV Medical Care
2008 ff - Service Needs and Utilization -NYC and Tri-County Region

Usefulness of CHAIN

- CHAIN major source of evidence for EMA's application for RW funding
  - 107 citations to CHAIN, 50 to eShare, 4 to MMP
  - CHAIN data featured Core Medical Services Requirement Waiver Request
- CHAIN major source of evidence for Needs Assessment, Comprehensive Strategic Plan
  - Over 200 citations, referring to 15+ reports
- CHAIN reports used widely by providers to inform service planning, for grant applications, to support advocacy efforts
  - 30% rent cap application and testimony
  - NY State Medicaid redesign to allow charges for supportive housing services

Usefulness of CHAIN

CHAIN reports provide evidence for policy making

Example: Need for housing/ benefits of housing assistance

- Housing is prominently featured in the national strategy document - esp. toward goal of "Increasing Access to Care and Improving Health Outcomes"
- HUD Strategic Plan FY2010-2015 explicitly recognizes the link between housing and health including HIV/AIDS
- HRSA lifts 24 mo limit to receipt of Ryan White housing assistance
- House and Senate resolutions recognizing that the lack of adequate housing must be addressed as a barrier to effective HIV prevention, treatment and care and requests increased funding
- HOPWA funding applications to congress

QUESTIONS?