# Missing the boat

Why do so many patients receive little or no HIV treatment in NYC?

# Is there a problem?

- As many as 10-30% of new HIV+ cases do not receive outpatient care within a year of diagnosis.
- It appears that many (5-8000) HIV+ persons in NYC receive little or no outpatient care.
- These are very crude measurements using the performance of a CD4 or viral load test as an indicator of HIV care. This is likely to overestimate actual use of antiretrovirals much less consistent and effective use.
- There is no systematic citywide data on how many persons are lacking effective care even though NYSDOH has ample data to address this question.

# Who disappears after HIV diagnosis?

- 695 new HIV cases had CD4<350 in 2004 (total 3700 new cases)
- 64/695 (9.2%) had no follow up data over the year following diagnosis suggesting no care.
- They were more likely to be male, young (20-29), black, and have an IDU history.
  - S. Kellerman, NYCDOHMH

# The view from the trenches

- The average inpatient HIV/AIDS census at CUMC is 25-30. At least half of these patients have longstanding HIV diagnoses but little or no regular HIV care.
- As the disease progresses they are repeatedly hospitalized with preventable illnesses.
- Ultimately most go to nursing homes or die, often never having received effective HIV treatment.
- Common cofactors in this population are unstable housing, untreated psychiatric disease and active substance abuse.

# Case examples

- HM

  48 yo gay man, lost steady job, HIV dx in homeless shelter. Started care but didn't like the way he was treated and dropped out. 2 yrs later had severe PCP re-entered care. Now doing well on HAART (vl<50).

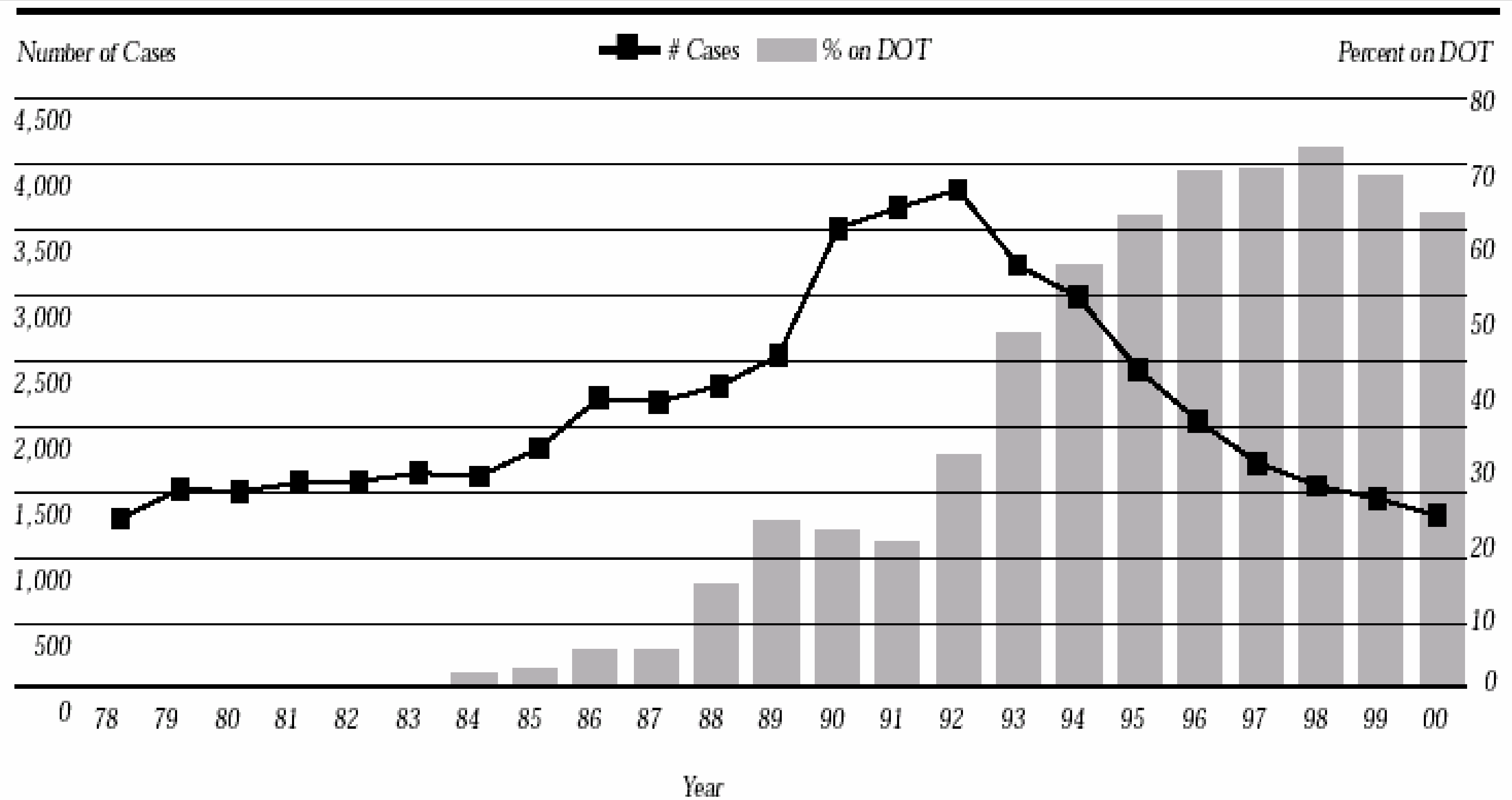
- JD

  37 yo alcoholic man with advanced HIV disease. Frequent admissions for alcohol and HIV complications. Never attends clinic; no HAART or OI Prophylaxis; Recently enrolled in 'frequent flyer program'. Still awaiting first clinic visit.

# What is or isn't the problem?

- Economic or geographic access barriers are critical in many other areas of US—not NYC.
- Primary care capacity is at least adequate and in many ways excellent. (AIDS center system)
- Co-ordination of care is problematic (case management is fragmented, unaccountable to medical providers). No one has oversight, responsibility and authority to deal with those who fall out of care or never enter it.
- Vital service sectors exist as isolated, vertical systems (housing, substance abuse, mental health).

# Deja vue: TUBERCULOSIS CASES ON DIRECTLY OBSERVED THERAPY (DOT)* NEW YORK CITY, 1978 - 2000



# The NYC DOHMH Proposal

- Utilize surveillance data to identify patients not in care.
- Registry??
- Enable re-engagement by last provider or DOHMH.

# Criticisms and controversies

- This isn’t needed; there’s no problem.
  - TB 1990
- Violates patient autonomy.
- ‘Big brother’ tactics will drive patients underground.
- Details:
  - who does the outreach
  - how complete will the data be?(clinic visits, prescriptions, adhererence?)

# This is only step 1

- Simply identifying and contacting out-of-care patients will not solve the problem (or make much of a dent).
- Care providers must be accountable for outcomes and given authority over needed elements of care.
- Better integration of services especially housing and medical care is critical (on site care; DOT etc.)
- More carrots? (incentives)
  - Economic impact dramatic
- More sticks?
  - How far do the parallels with TB take us.