

COMMITTEE ON THE DISCHARGE OF HOMELESS PERSONS WITH TB

Report to the New York State AIDS Advisory Council

Executive Summary

June 8, 1994

New York has become the center of yet another epidemic, tuberculosis (TB). Like HIV and closely related to it, New York City is the focal point for this disease. In 1993, in New York City, 3,235 new cases of active TB were reported for a case rate of 44.2 per 100,000 population; this is more than four times the national average. TB is accurately described as a disease of poverty; it is a serious illness occurring regularly in individuals whose immune systems are compromised due to HIV infection, intravenous drug use, other alcohol/substance use, malnutrition, advanced age or certain other medical conditions such as cancer. TB unevenly affects New York's communities of color; in 1992, 54.5% of all cases occurred among African-Americans and 27% among Latinos.

Where TB was once considered easily curable with inexpensive prescribed medications, it is no longer. The populations with TB disease have become poorer and more difficult to treat because of more complex social and medical problems. Increases in homelessness, substance use, and HIV-illness coupled with severely reduced disease control efforts during the 1970's and 80's within Federal, State and local public health agencies have resulted in increases in the number of people with active TB and decreases in the proportion successfully treated.

Incomplete therapy (which has been statistically correlated with homelessness and addiction) not only leads to repeated hospitalizations for those with active disease but to multi-drug resistant bacterial strains (MDR-TB). When compared to ordinary TB, the mortality rate of MDR-TB increases dramatically, the combination of drugs required to treat MDR-TB is more than twice as expensive and the length of required treatment often doubles.

Homeless New Yorkers and those who are HIV-positive are among those at highest risk for developing active TB. Those who are both HIV-positive and homeless face an enormous risk. Of all persons with active TB, the City Health Department estimates that 15 - 25% percent are homeless and at least 40% are HIV-positive.

Among the homeless living in shelters, as many as 60% are estimated to have TB infection and between 15 - 30% are estimated to be HIV-positive; the proportion who are dually infected is not known. For those living or working in congregate settings, particularly for those who are HIV infected, untreated or inappropriately treated TB disease within the environment presents a serious threat.

Despite identifiable accomplishments which have been made in TB control in NYC, the Committee agreed that much more remained to be done to assure that homeless persons with TB receive all services necessary to assist them in being successful in maintaining and

improving their health. The major problems that the Committee identified were:

- inconsistent application of methods to identify people with possible infectious TB, removal of them from congregate settings, and assurance of rapid medical evaluation and appropriate treatment;
- an unacceptably high proportion of cases not treated to completion;
- use of preventive therapy in far fewer people than could be expected to benefit from it;
- under-identification by hospitals of those patients who are homeless and those who are marginally housed;
- severe limitations, particularly for those not known to be HIV-positive, in the availability of supported housing programs as alternatives to shelter placement;
- challenges to effective communication and other linkages between hospitals and community-based providers; and,
- a poor definition of the role of community-based housing and social service agencies in TB control efforts coupled with inadequate training and resources to encourage their participation.

Recommendations

The Report makes nineteen specific recommendations to address these problems. These are summarized below:

- Increase efforts by public and private providers of services to the homeless to identify homeless persons who may have infectious TB and obtain an expeditious medical evaluation. A two-step process of cross-matching clients with the TB Registry and administering a standardized questionnaire about TB history and current symptoms should be consistently used at intake as well as periodically during the relationship with the client.
- Evaluate all existing arrangements for provision of medical services (including laboratory services) to homeless populations to assure that TB protocols and services are adequate and that Directly Observed Therapy is the standard of care.
- Expand efforts to identify individuals appropriate for preventive therapy and provide Directly Observed Preventive Therapy to them.
- Improve efforts within hospitals to identify individuals with TB who are homeless or marginally housed so that comprehensive discharge plans can be

made.

- Enhance linkages between hospitals and community service providers: by developing systems to assure that: homeless persons being discharged arrive at their housing placements; by providing a weeks worth of medications to patients at discharge; and by providing complete information to the community-based providers prior to discharge.
- Increase the availability of specialized housing and support services for persons being treated for TB by extending the Emergency Shelter Allowance for Persons with HIV-related illnesses and Their Families, the nutrition and transportation supplements, and the Comprehensive Medicaid Case Management (COBRA) to those who are not known to be HIV-positive.
- Develop and implement an information, training and technical assistance program for community-based housing and social service agencies serving persons at risk for TB.

For a copy of the full report, contact the Policy Unit of the NYS AIDS Institute at 5 Penn Plaza, New York, NY 10001.

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Report to the New York State AIDS Advisory Council

April 19, 1994

New York has become the center of yet another epidemic, tuberculosis (TB). Like HIV and closely related to it, New York City is the focal point for this disease. In 1993, in New York City, 3,235 new cases of active TB were reported for a case rate of 44.2 per 100,000 population; this is more than four times the national average. TB is accurately described as a disease of poverty; it is a serious illness occurring regularly in individuals whose immune systems are compromised due to HIV infection, intravenous drug use, other alcohol/substance use, malnutrition, advanced age or certain other medical conditions such as cancer. TB unevenly affects New York's communities of color; in 1992, 54.5% of all cases occurred among African-Americans and 27% among Latinos.

Where TB was once considered easily curable with inexpensive prescribed medications, it is no longer. The populations with TB disease have become poorer and more difficult to treat because of more complex social and medical problems. Increases in homelessness, substance use, and HIV-illness coupled with severely reduced disease control efforts during the 1970's and 80's within Federal, State and local public health agencies have resulted in increases in the number of people with active TB and decreases in the proportion successfully treated. Incomplete therapy (which has been statistically correlated with homelessness and addiction) not only leads to repeated hospitalizations for those with active disease but to multi-drug resistant bacterial strains (MDR-TB). When compared to ordinary TB, the mortality rate of MDR-TB increases dramatically, the combination of drugs required to treat MDR-TB is more than twice as expensive and the length of required treatment often doubles.

Homeless New Yorkers and those who are HIV-positive are among those at highest risk for developing active TB. Those who are both HIV-positive and homeless face an enormous risk. Of all persons with active TB, the City Health Department estimates that 15 - 25% percent are homeless and at least 40% are HIV-positive. Among the homeless living in shelters, as many as 60% are estimated to have TB infection and between 15 - 30% are estimated to be HIV-positive; the proportion who are dually infected is not known. For those living or working in congregate settings, particularly for those who are HIV infected, untreated or inappropriately treated TB disease within the environment presents a serious threat.

These facts have led to a great deal of concern among medical experts and advocates and were brought to the attention of the New York State AIDS Advisory Council. The Council established the Committee on the Discharge of Homeless Persons with TB. Specifically, the Committee was asked to review and make recommendations regarding the adequacy of discharge planning and the availability of post-discharge services for homeless persons being treated for active TB (including those who are HIV-positive, HIV-negative and HIV-unknown). Chaired by Robert Newman, MD, the Committee met six times to hear presentations, discuss issues and develop recommendations.

NEW YORK STATE DEPARTMENT OF HEALTH

The Committee met during a period of greatly increasing attention to the problem of TB. During the course of its deliberations, the public and non-profit sectors were actively working to improve efforts to: rapidly identify, diagnose, and treat to cure those with active TB; increase the safety of hospitals and other congregate settings; and extend preventive therapy to more TB infected individuals. The Committee acknowledges the accomplishments of both individuals and agencies which have been working diligently to address the TB epidemic. In fact, preliminary 1993 statistics released by the City Health Department indicate a significant drop in newly reported cases of active TB and in case rates. Assuming these statistical improvements are sustained, this can and should be seen as a testament to the effectiveness of the actions of many people and organizations. To acknowledge all TB achievements would be beyond the scope of this report, although a few seem particularly noteworthy and germane to the charge of the Committee:

- Due to increased environmental controls and vigilance on the part of physicians and other health care providers, the occurrence of nosocomial transmission of TB has been reduced.
- Since 1992, the availability of directly observed therapy (DOT) for persons with active TB has been expanded dramatically in health department clinics as well as through non-traditional providers of DOT including hospitals, community health centers, shelters, scatter site housing, soup kitchens and drug treatment programs. More than 1,700 people with active TB have been referred to DOT, more than 1,200 are currently participating and more than 250 individuals are reported to have completed their therapy while enrolled.
- City and State policy guidelines for control of TB in hospitals have emphasized the vital roles and responsibilities of hospital social work/discharge planning in referring homeless people being discharged with a diagnosis of TB to housing which incorporates social and medical follow-up including but not limited to DOT. Improvements have been noted throughout the system and the findings of the Greater New York Hospital Association's quarterly surveys are being used to develop action plans for further improvements in inpatient and follow-up care of TB patients.
- In a City-State partnership, a new \$6.3 million, 326 unit, scatter site housing and comprehensive support service program for HIV-positive persons with TB has been established and has very recently begun to serve clients.

Despite identifiable accomplishments, the Committee agreed that much more remained to be done to assure that homeless persons with TB receive all services necessary to assist them in being successful in maintaining and improving their health. Among the problems that the Committee identified were:

- Inconsistent application of methods to identify people with possible infectious TB, remove them from congregate settings, assure rapid medical evaluation and appropriate treatment
- An unacceptably high proportion of cases not treated to completion

- Use of preventive therapy in far fewer people than could be expected to benefit from it
- Under-identification by hospitals of those patients who are homeless and those who are marginally housed
- Severe limitations, particularly for those not known to be HIV-positive, in the availability of supported housing programs as alternatives to shelter placement
- Challenges to effective communication and other linkages between hospitals and community-based providers
- Poor definition of the role of community-based housing and social service agencies in TB control efforts coupled with inadequate training and resources to encourage their participation.

The Committee heard presentations by representatives of the City and State projecting the housing needs of homeless persons with active TB at the time of discharge from the hospital. According to the City, using IPRO and SPARCS data, the need for SNF-level care has been met and there is no need for additional SNF beds to care for persons with TB. For those who need housing, however, the picture is different. For 1993, the City projected a need for 1275 - 1414 housing units for persons discharged from a hospital with a diagnosis of active TB (723 - 795 housing units for those who are HIV-positive and 552 - 610 housing units for those HIV-negative or HIV-unknown). The State was in general agreement with the City's estimates considering them slightly low due to the fact that they were based on data derived from hospitalized persons only.

The Committee listened to housing providers, medical care providers from a variety of settings and government officials describe problems in the system as well as new approaches and models of care for this population with complicated medical and social needs. Members of the Committee took part in site visits to a number of shelters and supportive housing programs in New York City. The purpose of these visits was to assess how care is provided to persons with TB in the facility, determine what systems are in place to identify residents with TB and prevent spread of infection within the facility and assess which programs seem best able to meet the needs of homeless persons with TB. Visits were made to the AIDS Resource Center (supported scatter site), Manor Hotel (commercial SRO), Foundation House (non-profit emergency, supported group residential), Mount Eden (non-profit, permanent, supported group residential), the Charles H. Gay Men's Shelter (public shelter), the 30th Street Men's Shelter TB Unit (public shelter with support services for those with TB), the Franklin Men's Shelter (public shelter), and Bailey House (non-profit, supported group residential).

To develop recommendations the Committee broke up into three sub-committees: Identification Treatment and Follow-up; Hospital Discharge Planning; and Housing and Community Services. Sub-committee recommendations were then reviewed and finalized by the whole Committee.

The following are the final recommendations of the Committee.

RECOMMENDATIONS

IDENTIFICATION OF TB DISEASE

The identification, treatment and follow-up of homeless persons with TB disease, both previously diagnosed and undiagnosed, is the first priority.

1. Public agencies serving the homeless, especially the NYC Department of Homeless Services (DHS) and HRA's Division of AIDS Services (DAS), must routinely do two things: electronically crossmatch client names with the New York City Department of Health (NYCDOH) TB Registry and administer a standardized questionnaire regarding TB history and current symptoms. These should be done both on intake at a shelter, SRO or drop-in center and periodically during the relationship with the client. DHS and DAS, in consultation with the NYCDOH, should develop and strictly adhere to procedures for removing the person from the congregate setting and rapidly getting a medical evaluation should either or both of these identification methods indicate a possibility of infectious TB.
 - 1a. Programs and facilities serving the homeless, both public and private, including shelters, SROs, drop-in centers, day treatment centers, etc. must assure that clients are regularly screened for possible TB (both through electronic crossmatch with the TB Registry and through a standardized questionnaire) by DAS, DHS or in consultation with the NYCDOH. These facilities need to develop a system which can be carried out in-house for identification of clients with possible TB, removal from the congregate setting, rapid referral for medical evaluation and, as appropriate, referral to a hospital or specialized housing program.

TREATMENT OF TB DISEASE

The treatment of TB disease, particularly for populations like the homeless where drug resistance is high, is complicated. It is, therefore, especially important that this population receive ~~state-of-the-art~~ care by physicians experienced in treatment of TB. Timely laboratory services of high quality must be available to support physician treatment so that, based on drug sensitivities, correct medication regimens can be selected. Directly Observed Therapy (DOT) should be the standard of care for treatment and routinely recommended for homeless persons with TB. When the provider of DOT is different than the provider of medical care, a high level of coordination must be maintained between the two particularly around issues of patient compliance and implementation of the treatment plan.

2. In consultation with the NYCDOH, the DAS and DHS should review all existing arrangements for provision of medical services (including laboratory services) to homeless populations (eg. in public/private shelters and SROs) to assure that TB protocols and services are adequate. If services cannot be improved such that adequate TB care is provided on-site, all TB treatment should be handled by an off-site provider with sufficient expertise in TB management.
3. Primary responsibility for DOT should be maintained by the designated outpatient provider of TB care. The NYCDOH and NYSDOH should encourage linkages between outpatient providers and community-based organizations for DOT if it is determined that this will lead to greater likelihood of treatment completion for patients; careful coordination to assure continuous care of the patient is particularly important in this situation. DOT providers should meet the patient in the hospital prior to discharge in order to create a link with the patient, explain the DOT program, develop a plan for follow-up and reinforce the importance of participating in the DOT program.

PREVENTIVE THERAPY

The identification, preventive treatment and follow-up of homeless persons with TB infection is the second priority which should be addressed once substantial progress has been made in control of TB disease. Directly Observed Preventive Therapy (DOPT) should be the standard of care and routinely recommended for homeless persons with TB who meet the preventive treatment guidelines and are started on preventive therapy.

4. Unless a client has a documented history of active TB or a positive PPD, DAS and DHS should administer PPD/anergy tests on entry to the system. These should be repeated every six months for those found to be PPD-negative on entry.
 - 4a. Programs and facilities serving the homeless, both public and private, including shelters, SROs, drop-in centers, day treatment centers, etc. must assure that clients are receiving regular PPD/anergy testing through DAS, DHS or their medical care providers; if not, in consultation with the NYCDOH, these facilities need to develop a system to assure that their clients are receiving this service. All TB infected individuals who are medically appropriate should be offered DOPT.
 - 4b. Persons who are infected with both HIV and TB are a very high priority for preventive therapy. In order to identify these individuals, voluntary HIV counseling and testing should be readily accessible to all persons at high risk for HIV and TB. NYCDOH, NYSDOH and DHS should review the availability of HIV counseling and testing as well as follow-up services for this population and expand if necessary (also see recommendation #2).
5. NYS and NYC Department's of Health must circulate guidelines for preventive TB therapy and train physicians in their use.
 - 5a. NYS should extend Medicaid reimbursement to include DOPT.

- 5b. NYCDOH should develop a tracking system for follow-up of persons receiving preventive therapy to assure that preventive treatment is continued wherever patients are found in the system. The tracking system should also be used to conduct cohort analysis on preventive therapy completion in order to evaluate its outcome.

HOSPITAL DISCHARGE PLANNING

Ninety percent (90%) of TB is diagnosed in a hospital. In addition to assuring ongoing medical care post-hospitalization, one of the primary issues in discharge planning for homeless persons with TB is the early identification of those individuals who are homeless or "at risk" for homelessness because their existing housing arrangements are unstable; marginal housing arrangements often go unrecognized until the patient is ready for discharge. This is further complicated by the fact that, as a means of coping with limited staff resources, rather than assessing each patient some social work departments have established policies whereby the patients are evaluated based on a "risk" assessment. As a result, social workers may not see every patient admitted to a particular floor and frequently rely on the medical and nursing staff to identify problems which require their intervention.

6. An assessment should be made of NYSDOH's Preliminary Guidelines for Referral of TB Patients to Directly Observed Therapy Programs Upon Discharge from New York City Hospitals to determine if progress has been made in implementing the original recommendations and identify those areas where further follow-up action and coordination are still required.
7. Each patient with confirmed or suspected TB must receive a careful housing appraisal to determine the likelihood of homelessness so that adequate discharge plans can be made. Hospitals must continually reinforce and update, through staff education, procedures to assess the stability of a patient's housing upon admission to the hospital and periodically during hospitalization. Housestaff and medical students must also be trained to conduct a housing appraisal as part of the comprehensive medical/social history.
8. Hospital medical and nursing staffs should participate in educational programs to familiarize themselves with the facilities' TB discharge planning policies/procedures and the continuum of TB treatment resources to assure the prompt initiation of a social work and discharge planning evaluation of patients who may have TB disease.
- 8a. Hospitals must establish clear policies and procedures for identifying appropriate patients and making referrals to secure residential facilities; staff should be trained in their use. These policies/procedures should be consistent with those outlined by the Commissioner of Health of New York City.

9. NYCDOH should review the procedures and availability of the medical team evaluating referrals to the specialized TB shelter system (eg. 30th Street Shelter TB Unit) and streamline the process to prevent hospital discharge delays while at the same time assuring that prospective residents are clinically cleared for admission to a TB shelter.
10. Hospitals, in collaboration with the NYCDOH and the NYSDOH, must develop a system that assures that at least one week of medications is provided to those being discharged with a diagnosis of TB.
11. DHS, DAS and NYCDOH must develop a citywide system to insure that homeless persons with TB arrive at their housing placement following discharge from the hospital.
12. Hospital stays for persons with TB are often prolonged because of the dearth of appropriate housing options. Although housing units with comprehensive support services for people with TB must be rapidly expanded, until this occurs, individuals should not be kept in hospitals simply because support services (those not directly related to the medical treatment of TB) are not available in the community. Unnecessary hospital stays encourage elopement which minimizes the opportunity for appropriate discharge planning and impedes TB control efforts.
13. The State and City Departments of Corrections and Health must develop a discharge planning program for homeless persons being treated for TB within the jail/prison systems. Each person being treated for TB must receive appropriate discharge planning to include firm arrangements for DOT, referral to community-based medical care for TB, housing placement and other social service supports. Transportation, escort services, and/or other measures must be available to assure that homeless persons with TB leaving jail/prison get to the housing placement. State and City Departments of Parole/Probation should assist in efforts to assure treatment until cure by integrating DOT or reinforcing the necessity of participation in DOT.
14. To improve coordination and insure that outpatient providers of TB care as well as community-based providers of housing, drug treatment and social services have the information they need to provide appropriate care, hospital discharge planners should develop systems to notify these providers when a patient is being discharged to their organization. Additionally, the hospital discharge planner should follow-up with the patient or community-based care providers to insure that the discharge plan of care has been implemented.

HOUSING AND COMMUNITY SERVICES

A homeless person being treated for TB needs a stable housing setting to maximize completion of treatment. Emergency, temporary and/or interim housing placements for those who are homeless are frequent occurrences; as each move increases the chances that the person being treated for TB will be lost to follow-up and reduces the likelihood of cure, expediting placement in permanent housing must be the short-term rather than the long-term goal.

The supply of supported housing units for those who are non-infectious, particularly for persons with TB who are HIV-negative or HIV-unknown, must be increased. As there is no one best model for meeting the housing needs of people with TB, the development of a continuum of housing options ranging from rental assistance, to scatter site apartments, to supported group residential facilities, to residential substance abuse and mental health treatment centers, as well as to small specialized shelters is important. Priority should be given to expanding supported scatter site and group residential facilities within the voluntary sector.

15. NYS should extend the Emergency Shelter Allowance for Persons with HIV-related Illnesses and Their Families to homeless persons with TB who are HIV-negative or HIV-unknown in order that these individuals have the opportunity to secure non-shelter housing. Assuming that adequate support services have been made available, eligibility for the subsidy and its continuance should be connected to adherence to a TB treatment regimen. A transition period after completion of TB treatment should be included in the subsidy program to permit the assisted individual to arrange alternative housing (or a method to afford the existing housing).
 - 15a. NYC should extend the nutrition and transportation supplements now available to those who are HIV-positive to homeless persons with TB who are HIV-negative or HIV-unknown.
16. An assessment to determine support service needs must be completed before an individual with TB is assigned to housing. Whenever possible, a housing placement should be based on the needs of the person and the support services necessary to maximize the individual's ability to be successful in TB treatment. As appropriate, a housing placement should incorporate or secure referral to DOT, substance abuse/alcoholism treatment, mental health counseling, primary health care, as well as child care, vocational rehabilitation, and services for victims and perpetrators of domestic violence. NYS and NYC should insure adequate availability of these services for all persons who require them.
17. DHS and DAS should make placements in commercial SRO's only when no other housing option exists or when the individual explicitly indicates a preference for this type of housing. Persons with TB should be placed only in those commercial SRO's where DOT is available on-site.

- 17a. Sufficient resources should be made available to the NYCDOH and other providers to extend DOT to all individuals being treated for TB who are residing in SRC's.
- 17b. The agency making a referral for housing must also make other necessary services such as mental health and substance abuse treatment available.
18. NYS should extend Comprehensive Medicaid Case Management (COBRA) to all persons with TB as a means of financing a system of care coordination to assure continuation of the TB treatment regimen, adequate and continuing linkages between the hospital and community-based providers of post-discharge services, and periodic re-evaluation of service needs. Any new program of TB case management must be closely coordinated with the NYCDOH.
19. NYCDOH and NYSDOH should develop and implement an information, training and technical assistance program for community-based housing and social service agencies serving persons at risk for TB. Environmental standards, employee health, and support to the client with TB are areas of particular interest and concern. NYCDOH and NYSDOH should also assess the need for resources needed by community-based housing and social service agencies to implement recommendations regarding environmental standards, employee health and client support. These resources must be made available.

Appendix

The following individuals were members of the Committee on the Discharge of Homeless Persons with TB. Although the Committee achieved consensus on its findings and recommendations, not every individual participated in every meeting nor necessarily agreed with everything in the final report.

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The following people served as resource people to the Committee, were invited to each meeting and to participate fully in the discussions. As above, not every individual participated in every meeting nor necessarily agreed with everything in the final report.

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