

Mental Health: The Neglected Epidemic

Convening and promoting a dialogue among consumers, providers and policymakers



Northern Manhattan Community Voices Collaborative
Difficult to Cover Services Working Group

Community Voices is one of 13 learning laboratories that are part of the W.K. Kellogg Foundation's five-year Community Voices: Health Care for the Underserved National Initiative

Executive Summary

Mental illness is a major, and largely unaddressed, problem both nationally and in northern Manhattan. Although the 1999 Surgeon General report noted that fifteen percent of the adult population used some form of mental health service during the year, nearly half of all Americans who have a severe mental illness do not seek treatment. Northern Manhattan, home to an estimated population of 400,000 is among communities across the nation faced with daunting mental health challenges. Northern Manhattan is comprised of Central Harlem and Washington Heights/Inwood, two communities well known for having low employment rates, high incidences of poverty, and poor health indicators; all factors identified as contributors to poor mental health.

Resources to address the epidemic of mental health problems in northern Manhattan are neither adequate nor equitably distributed. In spite of the community's significant growth in population, poverty levels and poor health indicators, the status of its mental health care system has not changed since the last community assessment conducted over a decade ago:

- Central Harlem and Washington Heights/Inwood receive from the Department of Mental Health the third and fourth smallest allocation of resources respectively, a disproportionate distribution.
- State legislation related to Medicaid neutrality that limit the expansion of services have hindered the ability of mental health care providers to meet the overwhelming need to expand services to meet demand.
- Providers continue to receive low reimbursement, while psychiatric emergency room visits have increased by 40%- mostly among children and adolescents.
- There is an increasing number of seniors suffering from untreated mental health related illnesses that are erroneously attributed to old age.
- Community-based providers feel they are disproportionately bearing the burden of caring for the uninsured.
- There is great need to carry out treatment in a culturally competent manner.

Many mental health problems are best prevented and addressed by adequate social service networks. These critical networks need to be strengthened and expanded. Notwithstanding the importance of social service networks, there is a critical shortage of mental health treatment capacity. Even if social services were massively expanded, existing psychology and psychiatry treatment services lack the capacity to treat individuals in need of these services. As a result, problems are addressed late and treatment is often sub-optimal with inadequate follow-up after crisis intervention. Expanding the capacity of the mental health system to meet increased demand in a timely fashion is critical.

This paper presents a series of recommendations aimed at fostering the development of provocative and innovative initiatives that address mental health funding, changes in local and state policies and service coordination. These recommendations call for an increased

commitment by local institutions involved in the provision of mental health services and research. Such commitment will not only benefit individuals with much needed services, but will serve as a way to amend strained relationships between these institutions and community residents.

Introduction

Mental health¹ has been labeled as a “neglected epidemic”² that is just recently receiving national attention. Despite scientific and technological advances, lack of knowledge about mental health disorders permeates in American society. In 1999, the mental health community received much-deserved attention with the release of the Surgeon General's report on mental health. This report reminded our nation of that poor mental health adversely impacts the lives of members in our respective communities.

Mental illness is one of the leading causes of disability and premature mortality, second only to cardiovascular conditions in established market economies such as the United States (World Health Organization, 1990). Over 15 percent of the overall burden of disease from all causes may be attributed to mental disorders. Chronic mental disorders (major depression, manic-depressive illness, schizophrenia, and obsessive-compulsive disorders) account for four of the top ten causes of disability.

The Surgeon General report noted that fifteen percent of the adult population used some form of mental health service during the year. Eight percent have a mental disorder and 7 percent have a mental health problem. Yet, nearly half of all Americans who have a severe mental illness do not seek treatment. It is estimated that 20 percent of the U.S. population is affected by mental disorders during a given year. About 28 to 30 percent of the population has a mental or addictive disorder. Based on data on functional impairment, it is estimated that 9 percent of all U.S. adults have mental disorders and experience some significant functional impairment.

Serious mental illness (SMI) is a term defined by Federal regulations that generally applies to mental disorders that interferes with some area of social functioning. About half of those with SMI (or 2.6 percent of all adults) were identified as being even more seriously affected, that is having “severe and persistent” mental illness (SPMI). This category includes schizophrenia, bipolar disorder, major depression, panic disorder, and obsessive-compulsive disorder. While the data on children, adolescents and older adults is scarce, the Surgeon

1 Mental health is a widely used term that covers a scope of meanings. In this paper we will refer to different aspects of mental health including mental illness and mental health problems. We define as mental illness those disorders of thinking, mood and purposive behavior that impair functioning. Mental health is the “successful performance of mental function” in all aspects of life. Mental health problems are those signs and symptoms of insufficient intensity or duration to meet the criteria for any mental disorder.

2 “Neglected Epidemics and the Reports of the U.S. Surgeon General: A Call to Action for Oral Health and Mental Health Disparities” presented at the 128th Annual American Public Health Association meeting (10/00) with panelists Surgeon General David Satcher, MD, PhD, and former surgeons general, Antonia C. Novello, MD, and Julius Richmond, MD.

General's report estimates that 20 percent of children have mental disorders with at least mild functional impairment. Federal regulations also define a sub-population of children and adolescents with more severe functional limitations, known as "serious emotional disturbance" (SED). Children and adolescents with SED number approximately 5 to 9 percent of children ages 9 to 17. In terms of older adults, estimates from the Epidemiologic Catchment Area Survey indicate that 19.8 percent of the older adult population has a diagnosable mental disorder during a 1-year period. Close to four percent of older adults have SMI, and just under 1 percent has SPMI. These figures do not include individuals with severe cognitive impairments such as Alzheimer's disease.

In response to the national focus on mental health and the need to mobilize communities in identifying, advocating and addressing mental health priorities, the Northern Manhattan Community Voices Collaborative, under the leadership of its Difficult to Cover Services Working Group, embarked on a thoughtful and interactive assessment of the mental health services delivery systems in northern Manhattan. The working group conducted a series of interviews with local mental health service providers, institutions and consumers and non-consumers of mental health services and their families. The issues that emanated from these dialogues reflected the complexities of a mental health system struggling to meet the needs of changing, culturally diverse and economically stressed community. Most importantly, reflected in this dialogue is the need for funding that would allow providers to address the inequities in the delivery of culturally competent care.

The Northern Manhattan Community Voices Collaborative has captured this community assessment and it is presenting it back to mental health providers, advocates, families and consumers as a work in progress. It is the goal of the Collaborative that the document will promote and convene dialogue among key community stakeholders to bring about suggestions and planned recommendations that address the improvement of the existing mental health system.

About The Northern Manhattan Community

The Central Harlem and Washington Heights-Inwood communities comprise the northern section of Manhattan. With an estimated population of 400,000, the Central Harlem and Washington Heights-Inwood community is home to a growing, ethnically diverse population. In Central Harlem, the majority (70%) of the population is African-American, with an increasing Latino community (estimated at 22% in the 1990 Census) and most recently

increasing numbers of Haitian and African immigrants. In Washington Heights-Inwood, the Latino population is estimated at 72%. Most residents are from the Dominican Republic with an increasing number of Central American immigrants.

In 1995, the fifth most frequent discharge among Washington Heights/Inwood residents attending local hospitals was psychiatric discharges. Meanwhile, in 1996, Central Harlem had the highest rate of alcohol abuse hospitalization and the second highest rate of mental illness hospitalization in Manhattan. To understand these rates, it is necessary to identify the psychosocial factors that affect mental health in northern Manhattan.

The northern Manhattan community is home to underserved populations with language barriers, low employment rates, high incidences of poverty, and poor health indicators. Both, Central Harlem and Washington Heights-Inwood have been designated as federal medical and dental manpower shortage areas.

Mental Health Service Delivery System

In northern Manhattan, local institutions, general practitioners, and a host of community-based multi-services organizations are the main providers of mental health services. While the provider community has been cognizant of the inadequacies in its mental health delivery system, many continue their efforts to provide care with the hopes of ameliorating the pervasive mental health crisis faced by the community. In discussion with providers, it was found that mental health conditions have not changed since the last community assessment conducted by the Neighborhood Based Alliance³. In fact the severity of the problems associated with mental illness, e.g. immigration stressors, unemployment, emotional and physical abuse, violence, poor housing, neglected health conditions, continue to permeate in the northern Manhattan community.

Section one of this report summarizes the challenges faced by providers in the delivery of services to vulnerable populations: children, adolescents, the elderly, the chronically mentally ill and immigrants. Providers shared how the current financing of mental health services limits their ability to expand care and looked at the impact of managed care in already weakened service delivery. Section two summarizes the main themes introduced during the focus group sessions with community residents. Recognizing the importance of

³ Strategic Neighborhood Action Plan, 1990. Assessment of the northern Manhattan community published by the Neighborhood Based Alliance, a network of community based organizations funded through the northern Manhattan Empowerment Zone.

the community's perception on mental health, the feedback offered by "lay" consumers/residents is critical in developing a culturally competent mental health workforce. The last section of this report is a summary of recommendations provided at the consumer, advocates and provider levels.

The recommendations noted provide for the implementation of provocative and innovative initiatives that address mental health funding, changes in local and state policies and services coordination. But most importantly, the recommendations are geared at strengthening the current mental health system and to foster genuine dialogue around mental health issues in the broader northern Manhattan community.

I. The Service Challenge

Providing care in multi-stressed communities is dependent on the availability of critical social services networks. In interviews with key informants, the community's readiness to provide care was of great concern. While community leaders understood the need to push for campaigns to remove stigma and address cultural competency/diversity issues, they stressed the need to exert leadership in the revision of mental health policies, services and financing. Many are cognizant that a multi-faceted approach is needed for the effective delivery of mental health services in northern Manhattan. To this effect, key leaders, advocates, consumers and providers noted the following among the issues hindering the community's ability to increase mental health service delivery capacity:

- Financing
- Diversity and cultural competence
- State legislation that limit expansion of mental health outpatient service delivery system
- Managed care

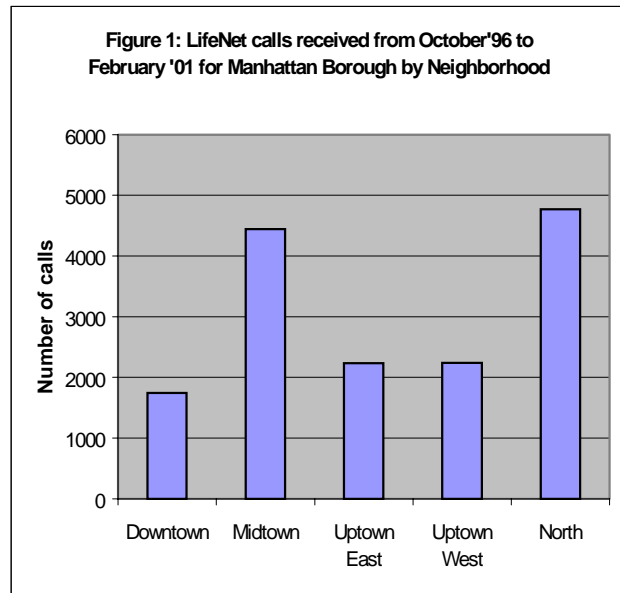
Providers interviewed characterized the mental health services delivery system as lacking the capacity to meet the mental health needs of community members and as having a poor infrastructure to provide effective follow up. Lack of capacity refers to waiting lists at local agencies, limited numbers of providers that can deliver culturally and linguistically appropriate services, and lack of services for specific populations - adolescents, children - within northern Manhattan.

The problem of long waiting list (or closed waiting list) is so severe that 54% of service providers interviewed expressed having waiting lists ranging from a week to four months. Anecdotal data indicates that waiting lists at major hospitals and the few bilingual providers that provide mental health services exceed the six-month period and in some cases, are closed out. Community mental health providers are aware of the need to increase capacity to meet identified service demand. Many recognize the need to conduct outreach and screening, but are apprehensive about doing so, knowing that the current system is not equipped to meet the demand for services. Their concerns are well founded considering

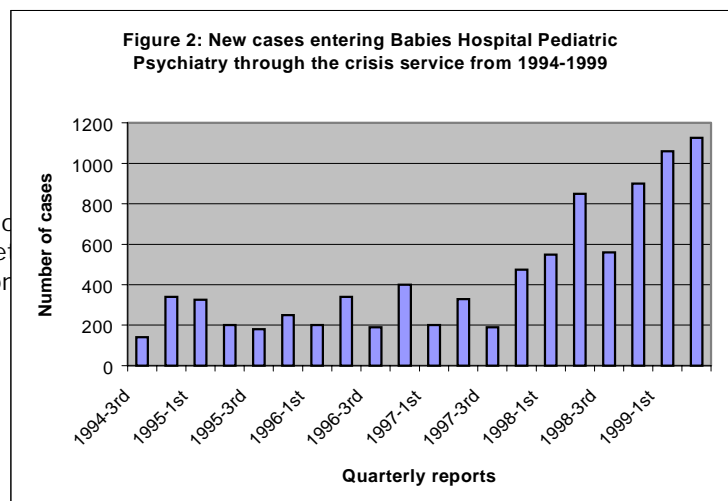
the calls received by the City's LIFENET/AYUDESE⁴ mental health hotlines are among the highest for the northern Manhattan area (see Figure 1).

Community-based medical providers are also feeling the impact of unmet service needs. A number of them are seeing patients with primary mental health concerns. These patients cannot be easily referred due to long waiting lists and patient resistance to psychiatric referral, yet primary care providers are not trained to treat patients with these ailments in a comprehensive manner. This results in high numbers of community residents being medicated with no psychosocial support to ameliorate the mental health symptoms beyond medication.

As mental health needs continue to be identified, the scarcity of bilingual, bi-cultural providers to serve minority populations continues to be a major barrier to care. Only two thirds of the agencies surveyed indicated that mental health services were provided in a language other than English. In the cases in which care was provided in other languages, it was not determined if the care was provided through bilingual providers or through interpreters.



- **Children:** Outpatient mental health services for children are scarce in northern Manhattan. Parents' and schools' demand for these services exceeds the capacity of current programs. As a result of the shortage in outpatient services, emergency services have become the main gateway to respond to such demand. Service data at Columbia Presbyterian's Babies Hospital reflect an increase in pediatric mental health related visits. In the past six years, these visits have tripled (see Figure 2). There are different levels of need for outpatient services among the



⁴ A service of the Mental Health Association of the City Department of Mental Health, Mental Rehabilitation, and Crisis Services, is a helpline staffed by mental health professionals within their geographical area.

pediatric population in northern Manhattan: (1) psychiatric assessment and treatment that cannot be obtained due to limited access to child psychiatrists, (2) services for mental health problems related to the stresses of immigration, including living in poverty and frequent separations from family members; (3) services to address mental health problems that have not reached a level of “morbidity” that can be diagnosed.

Inpatient services are also limited. There are only three units currently admitting children under 13 (Mt. Sinai, St Vincent’s and Bellevue) and five units admitting adolescents (Metropolitan, Bellevue, Mt. Sinai, St. Vincent’s and Payne Whitney) none of them in northern Manhattan. Children and adolescents up to age 16 awaiting hospitalization are managed by the Pediatric Psychiatry service in the Crisis Clinic by day and in the Pediatrics Emergency Room by night. It is not uncommon to wait more than a week in this holding pattern.

Due to the psychiatric bed shortage in Manhattan, children and adolescents are frequently admitted to inpatient units outside Manhattan (primarily in Westchester county and Queens), which presents significant barriers to a family’s meaningful involvement in treatment as well as financial hardship due to transportation expenses. In addition, many of the clinical services available outside the community do not have staff with the cultural and language competencies necessary to meet the needs of minority children.

Children must rely on their caregivers for identification of abnormal behaviors that may lead to mental illness. Stigma, fear and lack of knowledge about health care systems prevents parents from coming forward and seeking care on behalf of their children on a timely manner. Focus group participants raised the fear of being reported to children protective services agencies. They noted how in trying to seek help, the systems turns the problem back to them “they (children protective services system) turn things around and we are signaled as bad parents”. Latino and African American parents mentioned that they did not trust the system in diagnosing their children. “They don’t know our culture and they just want to study our children”, they recalled the media stories around minority children being disproportionately misdiagnosed because of their minority status.

Advocates alluded to the importance of educating parents on healthy child development and the need to avail the community with early diagnostic services that are culturally relevant. Children with behavioral or emotional problems have a hard time obtaining treatment due to limited service slots, waiting lists, and lack of specialized services within the neighborhood.

This is particularly true for children living in monolingual Spanish speaking households, children in need of psychiatric evaluation and treatment.

Finally, the particular service needs of children with mentally ill parents (or who have mental health problems) need to also be addressed. There are very few places where these children can be referred to. Many of the issues faced by this population are preventable or related to parenting. A larger group, are the children of parents with mental health problems more broadly defined and often undiagnosed – especially depressed mothers, substance abusers and family violence victims/perpetrators.

- **Adolescents:** Mental diseases are the second leading cause of hospitalizations among adolescents in Manhattan, second to pregnancy/related conditions⁵. Forty four percent of the Borough’s youth under eighteen years old live in northern Manhattan⁶. Youth in northern Manhattan have limited recreational and job opportunities, compounding with a failing school system, and high incidences of violence. Among adolescents, mental health needs related to their immigration status and acculturation are very important. For immigrant youth, the process of assimilation creates stressors that weaken the family structure and threatens the well-being of both parents and adolescents:

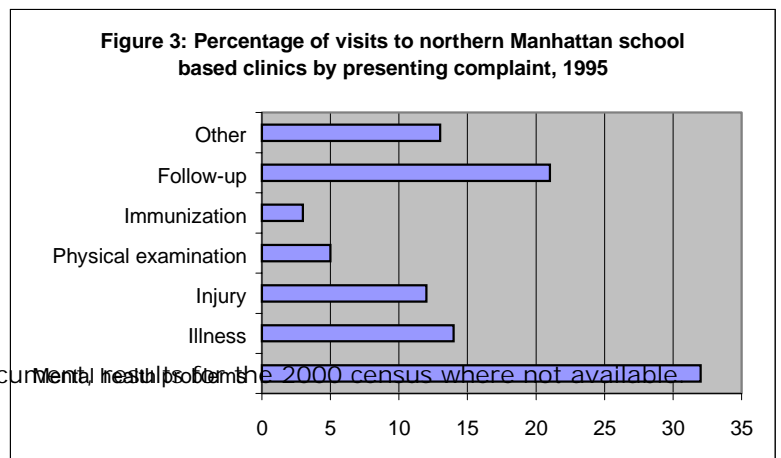
A 16-year-old female was brought to the pediatric emergency room due to a suicide attempt via an overdose with analgesics. This was her second visit to the emergency room, the first one was four months earlier when she had attempted to run away from home. On the second emergency room visit, she was sent to the adult psychiatry unit where she spent three days until she was hospitalized in one of the pediatric medical units. During a family session, with a Hispanic and a Caucasian therapist, the father expected the therapists to scold the young woman for her behavior. He identified with the Hispanic therapist but would not address the Caucasian therapist. Understanding the cultural and religious background of this father was crucial in developing a treatment plan.

The conflicts presented in this vignette related to cultural differences between parent and provider, assimilation, coupled with unresolved parent/child conflicts resulted in the hospitalization. The absence of referral systems led to a second hospitalization in this case.

For adolescents that are not linked to a provider or community-based

⁵ SPARCS data, 1997

⁶ 1990 Census data. At the release of this document, results from the 2000 census were not available



organization, schools are their primary source of mental health services or at least where symptoms are first identified. As many as one third of visits to school-based clinics by adolescents are mental health related (see Figure 3). While school-based clinic staff include licensed social workers and licensed psychologists who provide extensive care, including intensive case management, and long-term care, they face a lack of appropriate services to refer very seriously ill students to. Collaborative efforts are being explored to ameliorate this situation among the New York State Department of Health, New York State Office of Mental Health and the New York state Education Department to increase funding for mental health services in school based clinics. These efforts must be accompanied by increased services in the community where seriously ill students may be referred to.

- **Elderly:** Senior citizens (age 65 and older) constitute over 15% of the Central Harlem population and slightly over 11% of the total population in Washington Heights/Inwood. Over one third of the senior citizens in Central Harlem and 22% in Washington Heights/Inwood have incomes below the poverty level, compared to 19% in Manhattan⁷. Latino and African-American seniors in northern Manhattan are more likely to live in poverty than their Caucasian counterparts.

"An elder without support cannot survive in the community".

Many seniors living alone experience a poor quality of life. In Washington Heights/Inwood, 54% of African American, 50.8% of Caucasian and 31.1% of Latino elderly live alone⁸. As one of the local senior advocates pointed out, *"an elder without support cannot survive in the community"*. Seniors living alone are more likely to experience problems of daily living, which may lead to or exacerbate mental health problems. For example, socialization may be limited if an individual does not have proper access to treatment or therapy, particularly those diagnosed with dementia, Alzheimer's disease or other conditions that affect their functioning, which in turn may lead to the development of depression. Depression is difficult to diagnose in the elderly since symptoms may be labeled as problems of aging (i.e. reduced motor skills, changes in weight). Thus, there is a need to educate seniors and their families in identifying these symptoms. Although an option for seniors with depression or memory problems is to participate in studies out of local research institutions, those that do not fit protocols face long waiting lists and are left without care.

7 Data from the Northern Manhattan Aging Project, Stroud Center for Studies of Quality of Life, 1992-1994.

8 Ibid.

Homebound elderly have different needs than those who have the ability to access services on their own or with the help of their support network (i.e. relatives, senior centers).

Homebound elderly have an added need for transportation to access services, stronger social networks that can identify and meet needs at home and the services of interpreters for those who are monolingual. In addition, home health aides that look after homebound mentally ill patients lack the specialized training needed to address their particular needs. While the elderly in the Washington Heights/Inwood community have a strong and well-organized network of advocates (i.e. the Washington Heights & Inwood Council on Aging), similar coalitions are needed to strengthen advocacy efforts in the Central Harlem area.

- **Chronically mentally ill:** As State hospitals continue to lose funding and discharge chronically mentally ill patients, communities are asked to absorb the responsibility of providing necessary outpatient services. In a parallel manner, acute hospitals are required by Managed Care companies to reduce the patient's length of stay from an average of one month to 2 weeks or less. While it is important to be financially responsible, these discharge practices are not always accompanied by increased resources to support chronically mentally ill patients in the community.

Homeless mentally ill patients are especially affected by quick discharge practices. With this population, a shelter referral needs to be secured prior to discharge. In addition, mentally ill homeless patients and the providers that serve them are affected by the rising cost of medication. For example, the treatment schedule for a homeless mentally ill patient may include the use of an anti-psychotic medication priced at ten dollars per pill. If he or she is required to take two pills a day, the six hundred dollars per month needed to fill the prescription may make it impossible to maintain such treatment schedule.

The chronically ill population at large is especially affected by the recent "Welfare to Work" policies. The current system that identifies people who are out of work due to mental illness does not take into consideration treatment schedule and cost, making consumers weary of losing health benefits they may be receiving. For some consumers, employment training and job placement are an integral part of their treatment, however, employment options for consumers that take into account treatment needs are limited.

Among the chronically mentally ill, linguistic and cultural barriers are especially detrimental to treatment. Understanding mental illness within the social and cultural context in which the consumer was raised and lives makes the difference in terms of treatment compliance and follow up. Currently, there are requirements for mental health service agencies to offer

culturally and linguistically appropriate treatment, however many fall short of fulfilling this due to shortage of culturally and linguistically diverse providers.

Historically, mental health treatment has not been valued in an equivalent way with medical treatment. This may be related to the medical model's separation of body and mind or to the stigma associated with misinformation about mental illness. Advances in the field of brain research have resulted in treatment for conditions that ten years ago could not be treated. Yet the general population is not aware of these advances, as they would be, for example, of a new therapy to treat diabetes. Thus, aggressive education and anti-stigma campaigns that take into account the cultural and linguistic realities of individuals need to be supported and enhanced to reach out to this population.

- **Immigrants:** The northern Manhattan community is mostly comprised of immigrants. Many immigrant families are split between New York and their homeland. Stressors related to uprooting produce mental health problems that may escalate to mental disorders.

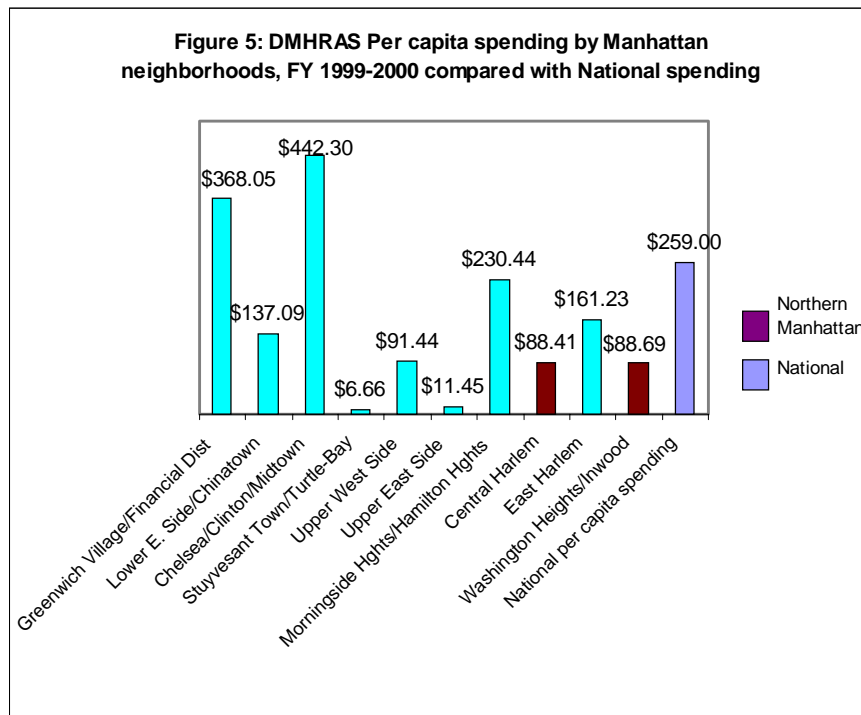
Mental health problems faced by immigrants are for the most part related to adjustment issues. Immigrant families do not have the support system, language skills and economic resources that would enable them to navigate an unfamiliar and bureaucratic system. Mental health stressors associated with migration challenge many immigrants as they seek new hope and advancement in search of the "American Dream".

An adult Costa Rican woman joined her husband who had migrated to the US several months earlier. For three months she was sad most of the time, had lost her appetite and refused to leave her apartment. The woman was very unhappy because she was unable to find a job, whereas in her country she had been working. She was admitted through the psychiatric emergency room and after 24 hours she was referred to a northern Manhattan community based clinic. She was in therapy for five months at the local community based clinic, although she had no insurance and was unable to pay for these services. During the course of treatment she was able to get out of the house, found a job and currently works part time.

In the vignette presented, the stressors related to unemployment and assimilation lead to a mental disorder, yet the case also highlights other issues related to immigrant mental health: uncompensated care provided by community based clinics. This is a burden on these agencies, yet providers continue to offer uncompensated services knowing that immigrants' preference for community based organizations is linked to a sense of safety at these settings (related to their immigration status) and their less complex organization (vis a vis the complex hospital system).

The financing of mental health services

The current funding level for northern Manhattan is below other areas that do not face as severe economic disadvantage (see Figure 4).



Central Harlem and Washington Heights/Inwood receive the third and fourth smallest allocation of resources respectively, a disproportionate distribution from the Department of Mental Health considering that according to 1996 SPARCS⁹ data, Central Harlem has the highest rate of alcohol abuse hospitalization in Manhattan (17.2 per 1,000 compared to 5.5 for Manhattan and 4.4 for New York City) and the second highest rate of mental illness hospitalization (14.2 per 1,000 compared to 7.4 for Manhattan and 6.3 for New York City) for adults 25 – 44 years of age. The demographics of the northern Manhattan community show the highest concentration of both seniors and youth, two of the most vulnerable populations. Taking in consideration the financial hardship, the devastating epidemic of substance abuse that has affected the community, and the lack of services it is shocking that northern Manhattan does not receive a larger allocation of resources.

The finances of mental health services provided through the New York State Office of Mental Health (OMH) are administered at the state level, while decisions on how funds are allocated are determined at the city level. In addition, in northern Manhattan there are three state community clinics that are funded directly through OMH. In the document that accompanies the 2001 budget, the governor proposes that the allocation of resources

should “assure a more cohesive and better coordinated system of care and expanding the capacity of the existing system.” In northern Manhattan, the financing of mental health services is affected by the following factors: (1) inadequate reimbursement rates, (2) staff turnover, (3) low cost of living adjustments to mental health budgets, (4) barriers to the expansion of services, (5) competing needs of clinical and preventive/supportive services, and (6) inadequacy of clinical administrative structures.

Inadequate reimbursement and low collection rates for Medicaid threaten the financial viability of community based mental health clinics. In a community based mental health clinic, an individual session is reimbursed by Medicaid at \$59 (\$18 per person if group session). But if these services are offered under Comprehensive Outpatient Program Services (COPS) or as a medically supervised service, the reimbursement rate would start at \$100. Moreover, these rates do not guarantee that a service will be reimbursed. On average a community-based provider can expect to receive 40 to 50 cents per dollar of service provided from Medicaid.

High rates of staff turnover are very common in northern Manhattan and were repeatedly mentioned by providers interviewed as one of the reasons for limited capacity of the system. Low salaries of mental health providers and lack of regular cost of living adjustments to mental health payment formulas are responsible for the high staff turnover in mental health care agencies, especially community-based clinics. A Coalition of Voluntary Mental Health Agencies survey, during the 1999-2000 fiscal year recorded a 42% turnover of nonprofessional staff and 50% of supervisory staff.

While yearly cost of living increase is customary for hospitals and nursing homes, the same does not hold true for all mental health services. In the Mental Health Budget for 2000-2001 a 2% cost of living increase was added for employees in residential programs, state employees received a 3% increase and hospitals received an increase based on the rate of inflation. Community mental health agencies (non-residential), however, are not scheduled to receive such adjustments.

For the last several years, New York State has had legislation that enforces “Medicaid neutrality” in the area of outpatient mental health services. Under this legislation, any expansion of outpatient mental health services must be balanced by a trade-in (or closing) of another Medicaid service provided by the applying agency. A service provider can not expand mental health service capacity without giving up some other service. In a

⁹ 1996 New York State Department of Health Statewide Planning and Resource Cooperative System.

community where demand for services is high as evidenced by waiting lists, and the high use of emergency services, this policy hinders providers' ability to request the expansion of necessary mental health services.

The challenge of allocating resources stems from the competing needs for clinical, and preventive/ supportive services, both extremely important components for a comprehensive delivery system to be effective. Funding provided by OMH is allocated either to provide clinical services (including adult services, licensed providers, ACT teams¹⁰ and children's services) or to provide community support (non-licensed services such as case management, rehabilitation, housing, shelters, clubhouses, psychosocial clubs and employment). For effective planning, both clinical, and preventive/ supportive services have to keep in context the living conditions in our community and their impact on mental health (i.e. immigration status, uprooting, acculturation, substance abuse, pervasive violence). In an effort to maximize available resources, the city Department of Mental Health has targeted funding to paraprofessional staff to provide prevention and consultation services. Participants in our discussion groups value these resources and feel comfortable accessing preventive services. Unfortunately, when these programs face an increased influx of patients with diagnoses that are out of the scope of their training, they are forced to refer patients to agencies that already have waiting lists or to the psychiatric ER because an increase in supportive/preventive services was not balanced by an increase in the number of clinical services available. Thus the challenge is to continue to provide preventive/supportive services while improving the capacity to provide clinical treatment.

The capacity of the system will be put to test during the transition into managed care. It is anticipated that managed care will dramatically decrease the amount of behavioral services available for Medicaid clients (limit number of treatment sessions per year; dramatically reduce hospital stays; transfer most detoxification clients to outpatient or "drive thru" services). It will also make such services much more difficult to access (through '800' phone numbers, certification requirements), tie such services to specific empirically validated protocols, and probably introduce into the community some of the larger behavioral care outfits who will have no real knowledge, history, credibility, or commitment to this community. For providers this means agencies spend much more time per client

¹⁰ Assertive Community Treatment (ACT) is an effective, evidence-based, outreach-oriented, service-delivery model for people with severe and persistent mental illnesses. Using a 24-hour-a-day, seven-day-a-week, team approach, ACT teams deliver comprehensive community treatment, rehabilitation, and support services to consumers in their homes, at work, and in community settings. A team can serve up to 100 clients.

(time needed to obtain treatment authorization) while offering less service (number of therapy sessions). They also receive a lower fee per service; have an increased amount of paperwork load; struggle with '800' numbers and certifications. In addition they must expand and automate billing, record keeping, data collection, and prepare for budget shortfalls, unhappy staff, inadequately treated clients, and managed care entities that set rates, procedures and treatment philosophy.

In addition, marked financial instability arises from a client base that is continually changing as to its Medicaid/insurance status. This depends on a host of variables including unpredictable managed care infiltration, clients' lack of awareness of their eligibility for Medicaid, immigration status of clients, loss of public assistance benefits and the erroneous belief that Medicaid has also been discontinued. It should be noted that due to the strong tradition of serving the community regardless of capacity to pay, neighborhood clinics frequently find themselves in the position of seeing large numbers of clients for which they do not get paid.

Along with all these challenges that affect service delivery, we need to consider the provider-consumer relationship, crucial in the delivery of mental health services. Racism, judgmental or insensitive staff, insensitivity for cultural differences and lack of empathy for the population served greatly undermines treatment. But even the most culturally competent staff faces an additional challenge when there is a difference in priorities (work vis a vis treatment) between providers and consumers. The development of treatment plans needs to consider consumers' perceptions of their illness, and the priority that is given to the illness or mental health problem in relation to other issues that affect their life and their community. If providers and consumers disagree on what the roots of the problem are, treatment and follow up can be undermined. For example, a provider may find that medication or group therapy may be called for in a treatment plan. But if the consumer is facing problems of daily living (work schedules conflicting with therapy appointments, stigmatization related to the use of medication, unstable or lack of housing), and these problems are not considered, then compliance with the treatment plan may be jeopardized.

Recognizing the importance of this relationship requires recognizing the importance of consumers as stakeholders in the development of their treatment plan, not as mere recipients of services. The following section presents the thoughts and reactions of both consumers and non-consumers on mental health and related topics.

II. "Just Talking": Community's Feedback

During discussion groups, consumers shared their views as stigmatized individuals and non-consumers from the perspective of how they saw individuals with mental illness or mental health problems. When asked to define mental illness/mental health problems, participants readily mentioned depression, substance abuse and an “emotional leak” or inability to perform daily tasks. Discussions on the causes of mental illness/mental health problems provided three perspectives: (1) a condition individuals are born with, (2) the result of one’s own actions, and (3) a character flaw.

The perception that some individuals are “born like that, those are the good crazies”, was supported by the idea that some individuals simply lacked the ability to bear their problems. Included in this category were individuals with neurological disorders. Individuals “born” with mental illness are thought of as deserving of treatment since “they are not at fault”.

When mental illness or mental health related problems are perceived to be the result of “one’s own actions”, then the empathy level for the person afflicted changes. Individuals perceived as having developed or “acquired” their mental illness are “bad crazies, they probably did it to themselves”. This label is held against MICA patients (Mentally Ill Chemically Addicted), patients with behavioral problems and substance abusers. This is not the case with physical ailments, “we would never blame a person as bringing a physical illness upon themselves, but rather as victims of an unfortunate accident, it just happens”. This points to the belief of the general public that mental illness is less real than a physically impairing condition.

The stigma attached to mental illness is further evidenced by the third perception: “character flaw”. The belief that individuals with mental illness lack sound judgment, are potential criminals, and cannot be relied upon to perform a job with the same efficiency than a person who is not ill was raised in the discussion groups. Participants stressed that media coverage of criminal cases that involve emotionally disturbed individuals contribute to stigmatization and serves to prevent afflicted individuals from accessing services.

While the above noted perceptions prevailed, community residents were cognizant of the environmental factors hindering their mental health. Community and environmental problems that were perceived by participants as influencing mental health included drugs, violence, domestic violence, discrimination, economic problems, housing, immigrant status, parents’ worries about their children’s future, unemployment and lack of training. “We are already stigmatized as black youth”, pointed out a young man who receives services in a community based clinic. Making reference to the shortage of housing stock, a woman

commented: “we feel we are being pushed away”. “Depression is an umbrella for all these problems”, said a participant explaining how the community’s environmental problems affected residents.

According to participants, making the decision to seek services is influenced by internal and external factors. Internal factors included the conviction that outside help is not needed. In addition, lack of knowledge on where to turn for help was a common response. Participants noted that “rehabilitation does not work, but rather your will power”. A woman recalled her struggle before she decided to look for services: “I feared being found crazy, I didn’t want to be caged”. “I thought they would take my children away if they knew what I was going through”, pointed out a mother who was suffering with depression.

External factors discussed by group participants included lack of insurance, limited number of places to be referred to, and cultural beliefs and perceptions about mental health problems both in their countries of origin and in the U.S. “Some people kept telling me: that what I was experiencing was “vagabundería” (being lazy and lacking dignity), and that I could put myself out of this if I put my mind to it”.

While the “own-will” perception is prevalent, the general public is being educated about mental health. Participants pointed out how the encouragement of concerned friends and relatives, primary care physicians or staff of community based and private agencies gave them the confidence to go for an initial evaluation and seek help.

But perhaps the most important outcome from our group discussions was to acknowledge that in our community, mental health is perceived as related to all spheres of daily life, not as a medical or psychiatric problem to be treated with medication. While participants did not articulate the need for mental health services in the various categories, they did stress the need to be able to talk to providers who were knowledgeable and understanding. The importance of “just talking” was stressed repeatedly in the focus groups “...it’s not about being crazy, but about being able to talk about anything that’s on your mind”. This was particularly important in the case of immigrants, in which isolation, assimilation issues and cultural adaptations are among their everyday struggles.

“...it’s not about being crazy, but about being able to talk about anything that’s on your mind”

III. Recommendations

The principal recommendation of the Surgeon General to the American people, is *“to seek help if you have a mental health problem or think you have symptoms of a mental disorder”*. Along with this recommendation, the report proposes a series of courses of action:

- to continue to build the science base;
- overcome stigma;
- improve public awareness of effective treatment;
- ensure the supply of mental health services and providers;
- ensure delivery of state-of-the-art treatments;
- tailor treatment to age, gender, race, and culture;
- facilitate entry into treatment; and
- reduce financial barriers to treatment.

Implementing these courses of action is particularly difficult to accomplish in northern Manhattan. In the northern Manhattan community, stigmatization is a barrier to get that help. Improving awareness of effective treatment is difficult when the supply of mental health services is limited and there is a shortage of providers. The delivery of state-of-the-art treatment cannot be ensured when entry into treatment is not guaranteed due to financial barriers. The following recommendations are based on the needs presented in this report. They are presented to policy makers, funding agencies and mental health service advocates in a call to action to increase the capacity to care for and serve vulnerable populations.

1. Building Capacity

The current mental health delivery system lacks the capacity to see all patients who need services at any point in time as evidenced by waiting lists at local agencies and heavy utilization of psychiatric emergency services. The community lacks providers that can deliver culturally and linguistically appropriate services, and specialized services for specific populations, such as children, due to under-staffing or financial instability. Although Medicaid reimbursement rates for mental health services have been recently revised, they remain low, as does city funding assigned to northern Manhattan. In addition, preparation for transition into managed care is a priority, as it is anticipated that the delivery of services will be affected.

Recommendations

- Increase Medicaid reimbursement rates for mental health services to obtain parity with other health services.
- Eliminate Medicaid neutrality legislation that limits the expansion of necessary outpatient services.

- Offer primary care providers training and technical assistance in diagnosing and treating common and uncomplicated mental health problems.
- Increase mental health services for children with behavioral or emotional problems.
- Establish inpatient services for children and adolescents in northern Manhattan
- Include cost of living adjustments on all mental health budgets.
- Guarantee that the expansion of preventive/supportive services is paralleled by an increase in clinical services.
- Increase the resource allocation for the northern Manhattan area.
- Expand employment training and placement programs for mentally ill that are treatment friendly.
- Increase funding for school-based clinics to support services related to mental health.
- Complement mental health services for chronically mentally ill individuals with parenting skills development and services for their children.

2. Improve Service Coordination

The current system of mental health care delivery is fragmented, making it difficult for consumers to navigate it. By improving the coordination of services through supportive services such as case management and social services, treatment compliance and outcome will improve. Well-coordinated services can act as a form of primary prevention in mental health, helping to decrease the need for hospitalizations. Collaboration among providers is the key to well coordinated services. In the past, attempts to develop effective collaborations among providers did not result in a well-defined coordination between providers due to competing interests for limited funding. Thus, the promotion of effective coordination needs to be paralleled by an increase in funding and resources.

Recommendations

- Expand mental health services provided in community-based agencies.
- Streamline the referral process to inpatient services from community based agencies.
- Strengthen the dialogue between providers from the northern Manhattan community and city/state mental health agencies
- Establish provider networks to facilitate information exchange on available programs, funding opportunities and new initiatives.
- Increase the number of case management programs for all populations (i.e. for parents with mentally ill children, adults, seniors).
- Implement a monitoring system to reduce the loss of public assistance and health benefits among chronically mentally ill individuals.
- Require specialized training for home health aides that look after homebound mentally ill patients.

3. Cultural Competency

In northern Manhattan, there is an enormous need for a system of mental health care that is culturally competent. Provision of services has to be flexible and sensible enough to understand that the cultural context in which consumers live is as important a variable as medication dosage. At the personnel level, the pool of available professionals who are

culturally competent is small, and their high demand makes them marketable in other communities. In order to expand the number of community residents that go into career in the area of mental health, the Department of Mental Health, Mental Retardation and Alcoholism Services (DMHMRAS) offers a program aimed at helping them obtain graduate degrees in Social Work from Hunter College to staff with a bachelor's degree and working at community based practices. Such program has a limited number of slots. In addition, the experience in northern Manhattan is that recent graduates who take entry level positions at community based clinics are forced to move on to better paying positions due to the burden of student loans. The following recommendations are aimed at helping retain and increase the number of culturally competent professionals.

Recommendations

- Provide incentives such as student loan forgiveness options to encourage recent graduates to take and maintain positions in northern Manhattan practices.
- Replicate the DMHMRAS scholarship program to train professionals in mental health area in other institutions of higher education.
- Train informal providers of supportive services, (i.e. clergy in faith communities) and staff of community-based organizations in identifying mental illness/problems and making referrals.
- Expand current training programs on cultural competency offered by the Department of Mental Health to include primary care practitioners and other support staff.

4. Prevention and Awareness

Efforts to increase public awareness around mental illness and mental problems are being carried out by DMHMRAS (i.e. the "Treatment Works" campaign). Social Marketing utilizes the concept of segmentation to divide a heterogeneous community in order to target educational materials to the specific needs of each subgroup of the population. Adapting these campaigns would increase the impact to target populations. Awareness education should be implemented not only at the community level (i.e. schools, senior centers) but should be extended to primary care and social services providers, and administrative personnel that are in contact with consumers at community based clinics and in institutions.

Recommendations

- Support the implementation of health education curriculum in schools that include modules and activities on mental health.
- Join established city and nationwide mental health awareness efforts and adapt them as necessary to our own community.
- Expand the dissemination of information and mental health resources to all social service settings in the community.
- Promote the creation of safe meeting spaces such as support groups, for the exchange of information on dealing with stressors and mental health problems.
- Conduct question and answer sessions with seniors on mental health.
- Perform depression screening as part of regular health check among the elderly.
- Implement parenting education programs that include modules on mental health and child development.

- Target awareness campaigns to specific population groups with different concerns: adolescents, women, men, and the elderly.

Seizing the Mental Health Momentum

Mental health service providers in the northern Manhattan community have been dealing with many of the concerns presented in this document for years. The ideas related to community based service delivery that are now emerging are not new. Yet, these issues are now starting to take national significance. This is an opportunity for providers, consumer advocates and community activists serving northern Manhattan to;

- ◆ rally around policy concerns,
- ◆ inform policymakers on how to adapt the current system of care delivery and,
- ◆ to promote changes that will improve the service delivery system.

Primary preventive measures can be geared towards reducing stressors identified as risk factors for mental illness, including the creation of “social spaces” where it is acceptable to ask for help with problems of daily living, and sponsoring community activities that promote quality of life. Secondary prevention should be aimed at identifying and providing early treatment for individuals who are diagnosed. This process requires coordination of services and the integration of gatekeepers and non-traditional providers. Tertiary preventive efforts should include more aggressive follow up and illness management to diminish decompensation, number of hospitalizations and visits to the emergency room.

In closing, none of the efforts geared to improving the delivery of mental health services in the northern Manhattan community will be effective if focus on the characteristics of the population served is lost. Providers that are fully bilingual and culturally competent but are trained in therapeutic skills that do not have the flexibility to take culture into consideration will continue to offer poor quality services. The new model of care needs to acknowledge cultural peculiarities and the special needs of the immigrant groups that make up the northern Manhattan community.

“Mental illness and less severe mental health problems must be understood in a social and cultural context, and mental health services must be designed and delivered in a manner that is sensitive to the perspectives and needs of racial and ethnic minorities”.

-Surgeon General's Report

Appendix A: Contributors

The preparation of this document would not have been possible without the continuous support of individuals from the community and the following organizations who participated in the interviews, assisted in the coordination of discussion groups and graciously permitted the authors to use excerpts from case stories to illustrate the text:

Alianza Dominicana's Family Center
Ambulatory Care Network Corporation
Center for Policy Alternatives
Children's Hospital of New York., Department of Psychiatry
Columbia University Mailman School of Public Health
Columbia-Presbyterian Critical Time Intervention Mental Health Program
Community Association of Progressive Dominicans, (ACDP)
Community Life Center, Inc. Headstart
Dominican Women's Development Center
Greater New York Hospital Association
Harlem Congregations for Community Improvement
Harlem Hospital Center's Psychiatry Department
Harlem House
Heilbrunn Center for Population and Family Health
Inwood Community Services
Mental Health Association of New York, Lifenet Hotline Network
New York City Department of Mental Health
New York Presbyterian Hospital, Division of Child and Adolescent Psychiatry
New York Presbyterian Mental Health Outreach Program for the Homebound Elderly
New York State Psychiatric Institute
New York-Presbyterian Hospital
Northern Manhattan Mental Health Council
Upper Manhattan Mental Health Clinic

Appendix B: Methodology

The data reported in this paper was gathered through key informant interviews, discussion groups, an inventory of services, and archival data. The key informant interviews were conducted with local providers of clinical local mental health services, supportive services for mental health consumers and community activists. These providers represent community-based clinics, health care institutions, community based social service agencies, advocacy and research groups at various levels of care, from case managers to psychiatrists to directors of services to advocacy leaders. The population served by these providers include children, adults and the elderly. The twenty-two key informant interviews were conducted from September 1999 to August 2000.

Eight small groups were gathered during April and May 2000. The discussion groups were small group conversations lasting about one hour, facilitated by a moderator following a set of guideline questions, leaving enough room for discussion of different issues arising in the process. A note taker was present during the session, and with previous authorization from the participants, all discussions were recorded. The discussion groups were conducted in clinical settings at community based clinics, institutions, and at community based agencies. Four discussion groups were composed of consumers of mental health services and the remaining four were groups of non-consumers. The topics covered during the discussions included:

- Definitions of mental health
- Issues participants considered as part of mental health
- Mental health needs in their community
- Participant opinion on people who seek mental health services
- Barriers to seeking mental health services
- Identification of mental health resources known to them

The notes and recordings of each discussion were revised and a descriptive report of each session was written down. In the subsequent analysis, statements were organized by subjects and age groups.

An inventory of mental health care agencies was carried out. The inventory included questions on types of services, target population, clients served, yearly visits, waiting period, staff and language capability. The list of providers inventoried was obtained from the District Resource Statement published annually by the New York City Department of Mental Health.

The archival data was obtained from the New York City Department of Mental Health, the Mental Health Association of New York, Children's Hospital of New York., Department of Psychiatry and the SPARCS database of hospital admissions.

Appendix C: The Northern Manhattan Community Voices Collaborative

The Northern Manhattan Community Voices Collaborative (NMCVC) is a partnership of institutions, community-based organizations and local health care providers working to improve overall health in Central Harlem and Washington Heights-Inwood. It is one of the 13 learning laboratories around the country under the W.K. Kellogg Foundation's *Community Voices: Health Care for the Underserved National Initiative*. The Difficult to Cover Services working group has a dual mandate to enhance access to both mental and dental health services.

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Alianza Dominicana, Inc.

Harlem Congregations for Community Improvement

Northern Manhattan Improvement Corporation

North General Hospital

CHILDREN'S DEFENSE FUND

WE ACT

New York Presbyterian Hospital

COMMUNITY PREMIER
PLUS

Community League of West 159th

Columbia University School of Nursing

Columbia University
Mailman School of Public Health

Community Life Center

HARLEM HOSPITAL CENTER

Children's Aid Society

The Valley

**Columbia University
School of Dental & Oral Surgery**

ISABELLA GERIATRIC CENTER

Ambulatory Care Network Corporation

R H E E D L E N C E N T E R

Community Impact

Council Health Center

Community DentCare Network

RENAISSANCE HEALTH CARE NETWORK

Harlem Health Promotion Center

New York State Department of Health

Northern Manhattan Coalition for Immigrant Rights

Abyssinian Baptist Church