Commission on the Public's Health System

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Executive Summary
Placing A Human Face On The Uninsured

Lack of health insurance is a problem nationwide, but in New York City it is approaching a crisis. Almost 30 percent of New Yorkers under the age of 65 have no health insurance. This figure is 50 percent higher than the national rate, and it is also growing more rapidly

Putting a Human Face on the Uninsurance Problem: To supplement and enrich the various statistical analyses of New York City's health insurance situation that are already available, the Commission on the Public's Health System undertook to put a human face on the problem by interviewing those most directly involved: the people living without coverage. Because this project was intended to include not only uninsured people who were receiving services, but also those who were going without health-care, it was decided to recruit the interviewees through the use of media and neighborhood outreach rather than by looking for them at hospitals and clinics. In the end, 51 New Yorkers were identified who were willing to share their stories, and each one was interviewed in depth by Elena Acosta, the Commission's Education/ Outreach Coordinator.

Profile of the Participants: Drawn from four of the five boroughs and from every age-group between 18 and 64, the participants included whites, African-Americans, Asians, and Latinos. People born in the United States predominated, but there were also immigrants from Asia, Africa, Europe, the Caribbean, and South America. Mirroring what earlier studies have indicated about the uninsured population as a whole, more than 70 percent of the survey participants were employed, and most had been working for many years. A few of the participants were virtually destitute, but most had regular though very modest incomes.

The Participants' Insurance History: More than 80 percent of the people interviewed for this report had had health insurance at some time in the past—either through their employers or under a public program like Medicaid. Some had lost their coverage by changing jobs, others by moving from full-time work to part-time, by going into business for themselves, by getting married or divorced, by leaving welfare, by growing too old for coverage under their parents' policies, or a variety of other life-changes. Ironically, a number of participants, having been eligible for national health insurance in their home countries, lost their coverage by moving to the United States.

Doing Without Care: Faced with the necessity of paying out-of-pocket for any care they received, most of the people interviewed said they simply went without medical services whenever possible. They reported giving up virtually all preventive care, and if they saw a physician or dentist, they rarely could afford to follow through on the medication or tests recommended. Even people with serious chronic conditions like asthma, mental illness, and diabetes said they had cut back drastically on their regular treatments and medication because they could not pay for them.

Cost Burdens: Despite these efforts, nearly all the participants said they had been forced at one time or another to seek care. For most of them, this meant going to one of the various public and private hospital clinics, Emergency Rooms, and community health centers that function as New York City's safety-net. Many of the people interviewed expressed dissatisfaction with the long waits and hurried service they encountered in such facilities, but given their finances, they felt unable to go elsewhere. Yet even in these locations, paying for help received was often a heavy burden, particularly if it involved emergency care or hospitalization. Some participants reported being denied service unless they paid their bill in advance. Others said they had accumulated thousands of dollars in medical debts, and a number were being threatened with court action. The weight of past debts and the fear of future ones clearly hung over their lives, reinforcing their determination to deny themselves all but the most desperately needed care.

A New Perspective on New York City's Health-Care System: These interviews offer a memorable window on the lives of 51 uninsured New Yorkers. They also offer a window on how well the New York City health-care system is serving the urban community.

Ideally, in a democratic society, a health-care system should be *inclusive*. Yet in the life stories told here we are forcefully reminded how many different and quite random circumstances can leave one standing outside the established circle of care.

A health-care system should offer *continuity*, yet these participants report chaotic medical histories, characterized by interrupted treatments, unfilled prescriptions, and service locations where a patient may never see the same practitioner twice.

A health-care system should be *responsive*, yet the widespread assumption that job-based insurance and Medicaid, between them, meet the needs of most non-elderly New Yorkers bears little relation to the current pattern of social and economic life in this city. In fact, there is a yawning gap between the two forms of coverage, and thousands of city residents, including the 51 people interviewed for this report, inhabit that gap.

Finally, a health-care system should ensure *visibility*, making certain that the needs of all community members are recognized and reflected in public policy. Yet these interviews suggest that there is a sizable share of the city's residents whose needs receive little systematic public attention. Instead, they are being addressed through an insufficient patchwork of public and private initiatives that only the most sophisticated consumer could navigate.

RECOMMENDATIONS:

1. Work toward universal health insurance

The many problems described in this report are eloquent testimony to this country's need for universal health insurance. It is clear that the incremental reforms achieved so far have left America's health-care system far from being able to provide the inclusiveness, continuity, responsiveness, and visibility that should be expected in a democratic society.

The need for universal coverage was cited repeatedly by participants in the survey, many of whom had had experience with national health insurance and/or universal access in their home countries. One observed: "I really do believe everyone should have some sort of coverage. If we can afford all this military expense, why not take care of the people?" Another man, an immigrant from Algeria, commented: "I really don't know much about health care in this country, but I know it's expensive and people are dying right now because they can't afford it."

2. In the interim, improve access to health-care among the uninsured in the following ways:

a. Monitor and improve existing public programs that provide insurance to the medically indigent.

Among the survey participants who have received Medicaid in the past, or who have attempted to apply for it, most speak eloquently about the many procedural obstacles that prevent eligible people from enrolling and staying enrolled. In addition, many individuals who may be eligible for Medicaid (or whose children may qualified for Child Health Plus) have not been made aware of the fact. It is essential, therefore, that a greater effort be made to reach out to those in need and to streamline application and documentation procedures so that eligible people do not slip between the cracks.

The recently-passed Family Health Plus program represents a start in expanding coverage for uninsured adults. Again, it will be important to make the enrollment process clear and consistent, and to ensure that those who are eligible are made aware of the fact. Even if this happens, however, it must be noted that this program will cover only a fraction of those in need. In fact, an analysis of the individuals who participated in this survey suggests that very few of them will qualify for Family Health Plus under current guidelines. Therefore, it is important to explore raising eligibility levels, especially for people without dependents, and covering legal immigrants. As a participant from Queens observes: "You have senior citizens who get Medicare, but some of us need some care before we become senior citizens."

b. Place greater emphasis on providing health services to the uninsured

Given the clear insufficiency of insurance coverage in New York City, the service needs of the uninsured should be given much more consistent attention than they receive at present. Additional funds should be allocated to "safety-net" providers, both public and private. At the same time, any hospitals and ambulatory care centers that receive extra money for serving the uninsured should be closely monitored to ensure that the funds are being used specifically for this purpose.

In addition, the survey findings make one thing very clear: when the uninsured cannot afford to pay for all the medical services they need, they are most likely to deny themselves preventive care. One woman from Harlem spoke for many other participants

when she explained that, to save money, she tried never to go to a doctor "unless it's a dire emergency." Yet there is ample evidence that waiting until one is in a "dire emergency" is bad for the patient and expensive for the health-care system. Accordingly, consideration should be given to allocating more Indigent Care funds to ambulatory settings, so as to make certain that uninsured individuals have access to free or very low-cost primary and preventive care.

c. Designate and support an organization that can act as an information-source and advocate for the uninsured

It is nearly impossible for uninsured New Yorkers to learn everything they need to know about their legal rights as patients, the various types of public coverage for which they may be eligible, the locations and admission criteria of the various providers around the city who offer low-cost care, and where interpretation services are available. Nor is such information necessarily available at the average clinic or Emergency Room. "Often," observes one participant, "you don't get anywhere because the receptionist at the general clinic doesn't know you, the receptionist at the internal clinic doesn't know you, you have to make five phone calls to get anywhere." She points out that many patients—especially the uninsured--need help with "the real practical aspects of health care: where to go, how to get it if you have less money."

To meet this need, it is recommended that a specific organization in New York City be charged with the responsibility of providing the uninsured with information, referral, and advocacy, and also serving as a source of information and education for community agencies that assist the uninsured. The designated agency should be given the institutional and financial support necessary to carry out this important endeavor.