

Minority Elderly Access to Health Care and Nursing Homes

New York State Advisory Committee
to the U.S. Commission on Civil Rights

EMBARGOED UNTIL October 30, 1992

November 1992

This factfinding report of the New York State Advisory Committee to the United States Commission on Civil Rights was prepared for the information and consideration of the Commission. Statements and viewpoints in this report should not be attributed to the Commission but only to the participants in the factfinding meeting, other individuals or documents cited, or the Advisory Committee.

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Letter of Transmittal

New York State Advisory Committee to the
U.S. Commission on Civil Rights

Members of the Commission

Arthur A. Fletcher, *Chairperson*
Charles Pei Wang, *Vice Chairperson*
William B. Allen
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Wilfredo J. Gonzalez, *Staff Director*

Almost 30 years ago, the New York State Advisory Committee issued a report on how hospitals in the Buffalo area served blacks. In a May 1964 report the Advisory Committee found that 7 of 22 hospitals implemented policies or practices that tended to discriminate against blacks. The 1992 report being transmitted is based on a forum held in Buffalo on October 27, 1990, a second forum in New York City on December 4, 1991, and a review of related documents. It opens with a brief discussion of the level of access the poor and minorities have to health services, then examines in more detail how nursing homes in New York State treat the minority elderly in need of long-term care; unfortunately the Committee again finds evidence of policies or practices that have discriminatory effects.

In the course of the forums, 18 specialists appeared including the deputy speaker of the State Assembly who chairs its committee on the minority elderly, a physician-advocate for a national health program, scholars who have studied the health needs of the black elderly, several State and county officials, a Regional Director of the Office of Civil Rights of the U.S. Department of Health and Human Services, top executives of associations of nursing homes, advocates for the elderly, and others. Several statements were also submitted for the record.

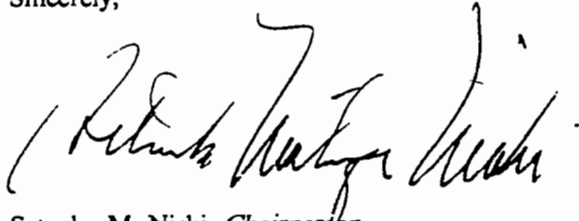
All agreed that the minority elderly are among the most vulnerable members of society. Two speakers outlined the failings of the U.S. health services system which disadvantages the poor in general. A team of university researchers reported on the extent to which the needs of the black elderly go unmet. Two spoke of the plight of the Hispanic elderly. Public officials, the head of a nursing home association, and a consumer advocate agreed that the elderly who are dependent on medicaid for health care are less likely to gain admittance to nursing homes than those able to pay upon admittance, a situation disproportionately placing the minority elderly at a disadvantage. Perhaps not surprisingly, only a fraction of nursing homes are owned or managed by minorities.

However, whether discrimination on the basis of race or religion is the key factor remained an open question for some who felt that the limited evidence available does not necessarily warrant such a conclusion. To begin with, data by race or ethnicity are not collected on who applies for nursing home admission and who is denied. At the same time, a U.S. district court has already ruled that dependency on medicaid exerts a disparate and adverse impact on black nursing home applicants.

In view of what was learned during the two forums, a review of the statements submitted, the district court ruling, and recent literature on the subject, the Committee generally finds it reasonable to suspect that in New York State, discrimination on the basis of race plays a role in the rejection of at least some minorities by the nursing homes to which they apply for long-term care. This report and its findings and recommendations were approved by the Committee by a unanimous vote.

With a steady increase in the graying of America, we trust that you share our hope that discrimination adversely affecting the minority elderly seeking long-term care will be stemmed before the dawning of the new century.

Sincerely,

A handwritten signature in black ink, appearing to read "Setsuko M. Nishi". The signature is fluid and cursive, with a large initial "S" and "M".

Setsuko M. Nishi, *Chairperson*
New York State Advisory Committee

New York State Advisory Committee to the U.S. Commission on Civil Rights

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Bronx

*Member who moderated October 27, 1990 forum.

**Member who did not engage in project.

***Former chairperson and member who presided over activities on October 27, 1990.

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The New York State Advisory Committee wishes to thank the staff of the Commission's Eastern Regional Office for its help in the preparation of this report. The forum and summary report were the principal assignments of Tino Calabìa with support from Michèle D. Morgan, Linda Raufu, and Edna Y. Rogers. Editorial assistance and preparation of the report for publication were provided by Gloria Hong Izumi. The project was carried out under the overall supervision of John I. Binkley, Director, Eastern Regional Office.

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Although the African American elderly were found to have greater needs for health care and health-related support services, they accessed services at approximately half the rate of their white counterparts.

-Arthur G. Cryns, SUNY Professor
Multi-Disciplinary Center on Aging
Buffalo, October 1990

NCCBA believes that the ultimate solution is a reform of the health care system to provide a national health insurance program which includes long-term health care.

-Samuel J. Simmons, President
National Caucus and Center
on Black Aged
Washington, D.C., July 1992

B A C K G R O U N D

Recent lawsuits in Tennessee and Pennsylvania have focused on nursing homes and whether the minority elderly experience racial bias when seeking access to long-term care in nursing homes.¹ To examine the situation in New York State, where nursing home beds are in short supply and long-term care is expensive, as it is in many other States,² two factfinding meetings were held by the New York State Advisory Committee which convened on each end of the State, that is, in Buffalo in October 1990 and New York City in December 1991.

It is of interest to note that almost 30 years ago, the Advisory Committee issued *Report on Buffalo Health Facilities*, a study which identified discriminatory practices in

¹Linton v. Commissioner of Health and Environment, No. 3:87-0941 (M.D. Tenn. Apr. 20, 1990). In 1990 the U.S. district court decided that Tennessee's policy of allowing nursing homes to certify less than all beds for medicaid violated the Medicaid Act and Title VI because of its disparate and adverse impact on blacks. See Tennessee Commissioner of Health and Environment J.W. Luna and Gordon Bonnyman, Esq., letter to Regional Director Thomas T. Williams, U.S. Department of Health and Human Services, May 31, 1990. Also Taylor v. White, CA No. 90-3307, 1991 U.S. Dist. Lexis 2472 (Filed Mar. 1, 1991). Plaintiffs contend that nursing homes in Pennsylvania discriminate against the poor and minorities by accepting those who can initially pay for care but ignoring those who at the outset must rely on medicaid. See Marc Kaufman, "Nursing Home Bias Is Cited; Disputed Report: Race Is Factor," *Philadelphia Inquirer*, Oct. 13, 1991 (hereafter cited as "Nursing Home Bias"), p. B-1.

²In May 1992 an economist and journalist wrote that the average cost in 1990 for a stay in a nursing home was "\$86 a day or \$31,000 a year—more than double the price in 1980. That ranges from around \$20,000 in rural areas to \$60,000 for red-carpet care in major cities." Jane Bryant Quinn, "Long-term Health Care: An Insurance Checklist," *Washington Post*, May 24, 1992, p. H-3.

seven nonprofit and charitable hospitals serving Buffalo.³ This new report briefly reviews the availability of health care for minorities but then examines an important segment of the health care industry, long-term care facilities. Such facilities are crucial to sustaining the lives of the elderly, some of the most vulnerable members of society. As the 1964 report did, this report also finds problems resulting in racial discrimination.

According to the 1990 decennial census, in New York State, there were 2,055,843 residents over the age of 65, a population which is larger than the individual populations of 15 States.⁴ Of the elderly in New York State, over 225,000 or 10.95 percent were black; about 4,100 or 0.2 percent, Native American; almost 40,000 or 1.92 percent, Asian American; almost 39,000 or 1.89 percent, other; and almost 128,000 or 6.22 percent, Hispanic.⁵ It may also be useful to mention that the State of New York was ranked only 34th when measuring the "healthfulness" of States, according to a 1991 study, *The 50 Healthiest Places to Live and Retire in the United States*, and none of the cities in the State was ranked among the 50 healthiest cities.⁶

Over the course of the two factfinding meetings, presentations were made by the deputy speaker of the New York State Assembly and by the New York City Council president through his special assistant, as well as by officials of executive branch agencies of the Federal, State, and county governments, heads of nonprofit advocacy organizations or agencies serving older consumers, scholars who have studied the plight of the minority elderly, top executives of associations representing nursing homes and hospitals, and a physician. Of the 22 speakers invited, 18 appeared, and written statements were submitted by two national organizations. The information from the factfinding meetings is supplemented and updated by references to the publications—many widely available—cited throughout.

³New York State Advisory Committee to the U.S. Commission on Civil Rights, *Report on Buffalo: Health Facilities* (May 1964), p. 10 (hereafter cited as *Buffalo: Health Facilities*). At the time, 22 hospitals in and around Buffalo served area residents. Though discrimination against blacks was evidenced at seven hospitals, the report pointed out that all hospitals accepted black patients, and the best medical care was available to them even in hospitals where discrimination occurred.

⁴U.S. Census Bureau, "1990 Census of Population and Housing; Summary Tape File 1, Profile 2 - Persons by Age, Race, Sex, and Hispanic Origin," June 28, 1991. This table was received from the Bureau of Economic and Demographic Information of the New York State Department of Economic Development.

⁵*Ibid.*

⁶Norman D. Ford, *The 50 Healthiest Places to Live and Retire in the United States* (Bedford, Ma.: Mills & Sanderson, 1991), p. 18.

Welcoming Remarks

Upon being introduced by State University of Buffalo professor Richard H. Cox, the Advisory Committee member who moderated the first factfinding meeting, New York State Assemblyman Arthur O. Eve, the deputy speaker of the New York State Assembly, welcomed the Advisory Committee to western New York and thanked the Committee for providing western New Yorkers an opportunity to speak about their concerns.⁷ Richard Clark, the director of the Buffalo office of the New York State Division of Human Rights, subsequently welcomed the Committee on behalf of Governor Mario Cuomo and the commissioner of the State division of human rights, Margarita Rosa.⁸

NEW YORK STATE ASSEMBLY DEPUTY SPEAKER

Following his welcoming remarks, assemblyman Eve made his presentation. In addition to his role as deputy speaker, Eve also chairs the legislative committee on the minority elderly. He noted that he had just arrived from a meeting of law enforcement officials from all levels of government, including the Buffalo police chief. He circulated sample statistics on violent crimes in Buffalo and pointed out that the police precincts recording the greatest violence "are basically in my assembly district which is predominantly African American, and the numbers are astronomical." He further observed that his district is troubled by drug abuse and poverty and that these afflictions exacerbate the problems of minority elders. He noted, too, that limited access to housing was also a serious problem adversely affecting minorities, including the older minority residents of Buffalo and western New York.

Regarding the minority elderly elsewhere--African Americans, Latinos, Native Americans, and Asian Americans--Eve said that he had scheduled hearings in New York City for mid-November 1991, during which those four groups would offer "an indication of the problems and solutions of the minority elderly there." On a national basis, he stated that whatever the elderly

⁷This statement and most others appearing in this report are from the transcripts of either the Oct. 27, 1990, factfinding meeting in Buffalo or the Dec. 4, 1991, factfinding meeting in New York City. Both transcripts are on file in the Eastern Regional Office of the U.S. Commission on Civil Rights in Washington, D.C. All other statements or information are from sources cited in the text and/or appropriate footnotes.

⁸Clark appeared as the lead State speaker for the Committee's factfinding meeting on the 1988 Fair Housing Amendments Act and public housing in western New York State. For the report on that topic, see New York Advisory Committee to the U.S. Commission on Civil Rights, *Shelter Issues: the New Federal Housing Amendments Act and Public Housing in Western New York* (August 1992). Commissioner Rosa was invited to participate or be represented in the December 1991 factfinding meeting, but her representatives phoned in their regrets on the day of the factfinding meeting.

need in terms of health care,⁹ social services, housing, nursing home, and inhome services, "the minority elderly suffer a greater need. The problems are particularly acute for the frail and the very vulnerable of all society." He described the frail and very vulnerable as 75 or older, in most cases having no pension, and a total annual income of less than \$6,000.

African Americans are the fastest growing population in New York State, and many of them are among the frail and very vulnerable, he noted. Of the elderly around the Nation, he estimated that 6 percent can be characterized as "frail and very vulnerable," but of the New York State elderly, 36 percent are frail and very vulnerable. "Because of oppression and racism, many minorities are vulnerable much earlier than 75. The life span of African Americans in New York--and in Harlem in particular--has been less than the life span of people in Aman and Bangladesh," he added.

More recently, a June 1992 issue of the *Wall Street Journal* reported that, "the life expectancy of black males slipped for the sixth year in a row, falling to 64.8 years in 1989 from 64.9 years in 1988 and 65.2 years in 1987. The increase in homicides of young black men was largely to blame. . . . [But] the death rate for heart disease per 100,000 population in 1989 was 205.9 for white men, and 272.6 for black men," according to information from the U.S. Department of Health and Human Services.¹⁰

During the factfinding meeting in Buffalo, the deputy speaker further observed that many minority elderly in New York State are acutely in need of inhome services; some are sick, and, because of failings in governmental policies at the Federal, State, and local levels, the chances are that they may become even sicker.

Unlike the average white senior citizen, many minority elderly do not have personal physicians . . . [and] take their pains and hurts to understaffed and overworked hospitals and community clinics, if they are able to get there. While the patient is suffering in the emergency room, the hospital is figuring out what medicaid will or will not pay. The bottom line is the same: "no pay, no stay."

He also asserted that medicaid patients are "often pushed out of the hospital . . . sick and alone into their homes" which may be drafty and substandard where those who are sick can add

⁹On health care, see also Amy Goldstein, "Conference Looks at Inequities in U.S. Health Care; Groups Aim to Mobilize Blacks on What Some See as the Civil Rights Issues of the '90s," *Washington Post*, Nov. 2, 1991, A-13 (hereafter cited as "Conference Looks at Inequities . . ."). Goldstein reports that a national group of specialists agreed that "Three decades after U.S. courts outlawed discrimination in hospitals and doctors' offices, black Americans continue to face inequities in life expectancy, health insurance, and access to medical care."

¹⁰Hilary Stout, "Americans' Health Improves but Blacks Suffer Higher Death Rates Than Whites," *Wall Street Journal*, June 26, 1992, p. B-4.

pneumonia to their list of potential ailments. "The result is a near crisis in inhome services throughout New York State for the minority elderly [who] need home care at 4 to 5 times the rate of white seniors."

According to the deputy speaker, in many areas, government concentrates "on the wrong end of the spectrum. We should not wait until the elderly get too sick to take care of themselves," but instead, should spend more resources on "the front end," that is, on education, decent affordable housing, and illness prevention and early detection. As it is, the minority elderly are often trapped in a downward spiral. They cannot get proper care either at home or in the hospital, and so their health deteriorates to the point where they cannot remain at home and must seek admission to a nursing home or to some other long-term care facility.¹¹

With regard to nursing homes, several years ago, the State of New York published "a report that clearly shows that minorities are in fact discriminated against in admissions to nursing homes here in New York State," the deputy speaker pointed out. "If you are white in New York State, your chances are about 3 times better than an African American trying to get into a nursing home. The same thing is basically true for all minorities." He then explained that when he personally began trying to help minority individuals gain access to nursing homes, he met with some success due to his position, but others working on their own did not meet with similar success. Part of the problem relates to the insufficient number of nursing home beds; "in this area we need many, many more than what the State of New York will allow."

The deputy speaker acknowledged that public monies are severely limited; nevertheless, many programs and services remain available, but minority communities are not organized well enough to take advantage of these resources. When minorities approach public agencies, the agencies explain that the resources have become limited and argue that some existing resources would have to be taken from the other communities in order to serve the needy minority communities. This led the deputy speaker to believe that any new funds meant for the aging must be targeted on the more needy minority communities. He will be recommending that a discretionary fund be set up for the State office for the aging that should then target it on those communities which have no services; moreover, an outreach effort must be implemented to inform the unserved elderly about available services.

Asked whether those who manage nursing home facilities are free to decide who shall be admitted and who shall be denied, the deputy speaker responded that they are not absolutely

¹¹One specialist defines long-term care as "regular assistance with medical care (nursing, medicating, physical therapy) or personal needs (eating, bathing, moving around) provided by someone outside an older person's family. There are many varieties of long-term care—ranging from part-time home care, to adult daycare, to different levels of residential facilities. Some long-term care is temporary. . . ." Joseph Matthews, *Elder Care: Choosing & Financing Long-term Care* (Berkeley: Nolo Press, April 1991) (hereafter cited as *Elder Care*), pp. 1/2-3.

free. But he also said that there is very little monitoring of the decisions made. From his experience, he pointed out that there are nursing homes sponsored by religious, sectarian, and ethnically based organizations and "in fact, they do make priorities with their own religion or their own ethnic [group]. . . . It is not legal to a degree, but that has been the practice, and it's been like that for years and years."

At the same time, the deputy speaker noted that a "special needs category" exists in the field of nursing homes, and he reported that on that basis a local group associated with the Grace Tabernacle Church embarked upon the ambitious goal of establishing a nursing home for African Americans to be operated by African Americans in a culturally sensitive way. He expressed gratitude to his colleagues among the western New York delegation who helped to provide between \$300,000 and \$400,000 to assist the Grace Tabernacle Church in its venture. In like manner, he had seen Italians in Boston start a nursing home because they sought to have a facility sensitive to the needs of the local Italian elderly. He told the Committee that:

I do not blame people for trying to take care of their particular elderly group. But government and the private sector must also say, "How do we encourage and assist other groups that do not have this sophistication and resource to also get into this business to provide culturally sensitive nursing homes for their particular community?"

In a July 1992 letter to Commission staff, Samuel J. Simmons, the president and chief executive officer of the National Caucus and Center on Black Aged, offered several recommendations to overcome obstacles faced by the minority elderly seeking admittance to nursing homes. To reduce the problems of insensitive treatment and also to encourage minority ownership, as mentioned by deputy speaker Eve, Simmons wrote that, "since minority access has been shown to be a problem, one solution should be to assist minorities with owning their own facilities, especially those which are based in minority communities." He added that incentives should be created for potential minority owners in terms of assistance with startup capital, tax relief, and increased medicaid payment levels for homes which serve a high percentage of minority patients.¹²

Concluding his remarks at the factfinding meeting, deputy speaker Eve voiced his appreciation of the fact that "some of the most prominent people in western New York" would be addressing the Committee. He repeated that his State assembly committee has launched a series of hearings and would soon be holding them in three boroughs of New York City to which he encouraged attendance by Committee members.

¹²Samuel J. Simmons, president and chief executive officer, National Caucus and Center on Black Aged (NCCBA), July 23, 1992 (hereafter cited as "NCCBA Letter"), p. 1. See app. A.

SUNY/BUFFALO MULTI-DISCIPLINARY CENTER ON AGING

Dr. Arthur G. Cryns is a senior research professor in the Multi-Disciplinary Center on Aging at the State University of New York (SUNY) at Buffalo. He explained that his research associate, Kevin M. Gorey, and he reviewed the literature available nationally on the utilization of health care by blacks 65 years of age and older in comparison with the utilization by whites of the same age. Gorey and he had also done several studies in New York State on the utilization of health care by the same two populations. Cryns said that their presentation essentially provides empirical data on the differences between black elders and white elders in terms of their demand for, and use of, primary health care support services.

His national figures provided a quantitative summary of black and white differences in access to geriatric and gerontological health care services as reported in currently available publications. Comparing the outcomes for blacks and whites, as seen in data from the U.S. Department of Health and Human Services, it became clear that the admission rates were 27 percent for whites but only 10 percent for blacks, indicating that nursing homes are being used almost 3 times more by the white elderly population than by the black elderly population.

As for admissions to hospitals and the number of days spent in hospitals over the previous year, Cryns said that the ratio tends to favor whites on the average of 2 to 1. "In other words, there is a 2-to-1 advantage for whites in accessing hospital care. In terms of physician contacts, whites enjoy access to physician care at a rate of 1.5 in comparison to a rate of 1 for blacks." When asked whether an individual encountered difficulties of any kind in accessing health care, practically double the proportion of black elders reported "great difficulty" when compared with their white counterparts. Thus, "in terms of access to, and utilization of, basic primary health care services, whites always have the distinct advantage over blacks," said Cryns.

Generally supporting Cryns's argument, a study appearing earlier this year in the *Journal of the American Medical Association* found that "white medicare patients are far more likely to have coronary artery bypass surgery than black medicare patients. . . . The white-to-black ratio for the operation was 3.5 to 1 for the United States as a whole."¹³ An even more recent article in the *Journal of the American Medical Association* reported that "blacks in the United States may be less likely than whites to get some expensive new drugs, even when both carry similar insurance. . . ."¹⁴

¹³David Brown, "Racial Disparity Found in Bypass Surgery Rate; Operation Far More Common Among Whites," *Washington Post*, Mar. 18, 1992, p. A-3.

¹⁴"Blacks Less Likely to Get Kidney Drug; Study Suggests Disparity Even When Whites Have Same Insurance," *Washington Post*, Sept. 16, 1992, p. A-17.

During the factfinding meeting, Cryns also pointed to “other rather disturbing trends” in terms of where people obtained their medical care, showing data indicating that black elders receive theirs from “public dispensaries of health care” at three times the rate of whites who enjoy much greater access to private health care. At the same time, Cryns’ review of the national literature revealed that blacks 65 years of age and older had a 3 to 1 chance of not surviving a hospital admission compared to white elders.

He said that one might hypothesize that white elders gain access to health care in significantly greater numbers than their black counterparts because the former may have worse health conditions. But Gorey and he examined the national literature comparing the physical well-being of white elders and black elders, and their review showed very clearly that “blacks do have more disabilities, more functional impairments and, in effect, do have a greater need for health care services by a rate . . . of 1.4 to 1.” Therefore, concluded Cryns, blacks are in fact the more disabled group, the one in greater need of services, and yet their access to services is “practically at a rate that is half that of the white population.”

Cryns further noted that Gorey and he examined the question of what factors covariate with the utilization of health care services, and one such factor is income. Compared to white elders, black elders have an impoverishment rate of more than 2 to 1 over the white population. Nevertheless, some argue that the black elderly access health care services less than their white counterparts because black elders enjoy more of an informal support system. According to this argument, “Family, friends, and maybe even neighbors take care of their needs and, thus, there is no reason for these elderly to access the formal care system in great numbers.” A related argument holds that the black “family will support an elderly individual or member better than the white family.”

Cryns pointed out, however, that their research does not corroborate such arguments. “Family and neighbors coming to the aid of a dependent elder is not greater for blacks than it is for whites.” In a similar vein, another scholar—one who happened to cite the Committee’s 1964 report on discrimination in Buffalo area hospitals in his article, “Population Ecology and the Racial Integration of Hospitals and Nursing Homes in the United States”—also found that “researchers have generally reported either inconclusive or modest differences in the amount of informal and family support available to black and white elderly.”¹⁵

During the factfinding meeting, Cryns summed up his presentation by stating that:

¹⁵David Barton Smith, “Population Ecology and the Racial Integration of Hospitals and Nursing Homes in the United States,” *Milbank Quarterly*, vol. 68, no. 4, 1990 (hereafter cited as “Population Ecology and Racial Integration of Hospitals and Nursing Homes”), pp. 584-85.

although African American elderly were found to have greater needs for health care and health-related support services, they accessed services at approximately half the rate of their white counterparts. This black-white difference in the use of formal services cannot be explained by greater access to various sources of informal services. . . . Being impoverished at the rate of twice that relative to white elders, all blacks may be less able to pay for the out-of-pocket deductibles on insurance premiums.

Cryns then spoke of his studies on black elders in New York State, including the central cities of Albany, Binghamton, Buffalo, New York City, Rochester, and Syracuse, referred to by deputy speaker Eve. He said that the question was posed: who are the dependent elderly? To arrive at an answer, 17 characteristics were examined including: whether the person is highly dependent on the health care system because of chronic disabilities, whether the person is in need of special services at home or frequently has unmet social services needs, and the like. If the person met 3 or more of the 17 criteria, the person was characterized as vulnerable.

Applying the standard to the white elderly, it was found that the percentage of dependent elderly was 6 percent, but it was 4½ times as high for the black elderly. Looking further, it was seen that vulnerable white elders used nursing homes 5 times as much as do vulnerable black elders at least in terms of admissions and being on a waiting list for admission. Regarding hospital use, the white elderly were admitted at a rate 1½ times the rate of the black elderly, and, regarding access to inhome services such as nursing care, personal care, delivered meals, and other such services, white elders enjoy an almost 4-to-1 advantage over black elders. Similarly, black elders are almost 1½ times more disadvantaged when it comes to having their needs met in terms of help with food shopping, getting food stamps, and having meals prepared. Cryns emphasized that:

it is not a difference in need that makes for this difference in access to services by these two particular subpopulations [of the vulnerable white elders and the vulnerable black elders]. It is a very baffling fact to find that two groups that basically have equal needs, nevertheless, have these large and consistent differences in access to health care services that could alleviate their particular needs.

Cryns and Gorey also looked for available socioeconomic resources and informal social support and found again that black elders and white elders are much alike. In terms of health care coverage, there is only a very slight preponderance of medicaid dependency among vulnerable blacks compared to vulnerable whites. But when these subpopulations are compared with their total populations, the indicators again show a much higher representation among blacks compared to the representation for whites. "There must be other reasons than need that explain the differences in the utilization of primary and of long-term health care services by black elders and white elders." However, neither the studies by Cryns and Gorey nor by others

indicate "what the specific impediments are that make blacks at a disadvantage over whites."

Cryns then summarized several recommendations. First, the "proper criteria for equitable allocation of health care and related resources ought to be need based rather than population based." He noted that it is often supposed that, if blacks represent 15 percent of the total population of elders in a given service area, then a provider agency is demonstrating an equitable delivery of service if 15 percent of its clients are black. Cryns pointed out, however, that this argument falsely assumes that the need for service is the same for all population groups. According to his research and other professional literature, "African American elders access aging services less extensively than do their white counterparts despite the fact that their service needs are frequently multiples of the [needs of white elders.]"

Second, said Cryns, "the key to service delivery to minority elders appears to be outreach." He reminded the Advisory Committee that black elders have a vulnerability rate $4\frac{1}{2}$ times that of white elders, and by its very nature, vulnerability is a characteristic of those elderly "least able to get out and access needed services and who are less likely to have available to them the kind and volume of informal supports that could conceivably substitute for formal services." He added that "nearly two-thirds of all vulnerable black elders in New York State admit to unmet needs in transportation and that nearly one-half of them, 42 percent, have unmet needs in their ability to purchase basic foodstuffs." Thus, those in this high-risk elderly subpopulation "live shut-in lives and are generally unknown to the service bureaucracies that could alleviate their needs."

Third, with regard to legislation, "a national health insurance plan is needed that has as its primary benefit guaranteed access to care for those with demonstrated needs," Cryns emphasized. If this should not find sufficient support among legislators, then at a minimum there must be "a halt to the continuing erosion of benefits under the federally funded medicare, medicaid and other health care programs, a process begun in the 1980s and continuing unabated in the 1990s." He noted that a substantial portion of black elders fall into the category of the near poor. Not able to qualify for medicaid, they also are unable to pay the premiums for supplemental Medi-gap insurance or other out-of-pocket deductibles frequently associated with governmentally regulated forms of health care. He expressed pleasure to see that under a then-new Federal budget agreement, modest provisions had been made to aid the near poor.

On the other hand, Cryns was not favorably impressed by the nursing home case-mix reimbursement system because it did not appear to achieve its intended effect of increasing admissions to nursing homes of minority and other elders unable to pay when they are ill. He was similarly displeased by the hospital prospective payment system because, by mandating flat rate reimbursements for medical care of specific conditions, that system may ultimately have a discriminatory impact upon the medically underserved. He said that the research literature

indicates that black elders have a significantly greater number of comorbid conditions than do white elders. Consequently, black elders are at greater risk of falling victim to complications when being treated for the same illness suffered by white elders.

Moreover, since black elders have less access to ongoing medical care from a personal primary care physician, they are more likely to be more severely ill upon finally coming to the attention of the health care system, Cryns stated. For this reason he believed that both reimbursement systems should be evaluated for their effects upon the quality of health care delivered to the Nation's poor and minorities.

Relative to the many problems confronting minority elders, little is actually known, and what is known is limited and fragmented, according to Cryns. Thus, he pleaded for more research, saying that "what is needed most is a representation of all minority elders in currently ongoing studies in numbers sufficient to draw scientifically valid generalizations about them." Current national health studies of older populations are faulty in that the proportional representation of black elders in these surveys ranges from 6.6 percent to 10.7 percent of the respondent samples studied. Cryns further specified the need for longitudinal studies rather than cross-sectional epidemiological studies of the black elderly. He said that, "only in this manner can one ascertain true age changes in the health conditions of this group and obtain a sufficiently detailed informational data base about its health-seeking behaviors and the specific impediments it encounters in obtaining the services needed."

NAACP/BUFFALO BRANCH

Daniel R. Acker, president of the NAACP/Buffalo branch, asserted that among the industrial democracies of the world only the U.S. fails to guarantee equal access to medical care and hospital services, with the more than 10 million Americans living below the poverty level having no way to cover the cost of needed health care.¹⁶ In a democracy, adequate health care is not a privilege of the few but a right of all, including the poor, said Acker, adding that the economic prosperity of the past decade was not shared by all segments of American society. Though some attained even higher levels of prosperity, others were reduced to poverty, as the gap between the rich and the poor became wider than it has ever been.

Speaking as a member of the board of managers of the Erie County Medical Center,

¹⁶During the October 16, 1992 meeting of the U.S. Commission on Civil Rights, Commissioner William B. Allen observed that medicaid, or Title XIX of the Social Security Act, provides medical assistance to the poor who are over age 65, to those disabled, and many others living at or below the poverty line. Commission Vice Chairperson Charles P. Wang agreed, noting, however, that individuals are not automatically covered but must apply, and many do not.

Acker explained that the center does not turn away anyone regardless of their ability to pay, and a large number of those receiving care there are minority elders. Alzheimer's disease poses many unsolved problems for those between the ages of 60 and 80, yet only a small amount of funding comes from the government to care for Alzheimer's patients. On the other hand, one encouraging development has been the enactment of the Disadvantaged Minority Improvement Act of 1989, said Acker. It set up an office of minority health and authorized \$10 million for 1991, \$12 million for 1992, and \$15 million for 1993. The U.S. Health and Human Services Secretary is authorized to fund public or private nonprofit organizations providing health information and education services. The Secretary is also authorized to make grants to help professional schools increase loans and scholarships to disadvantaged students.

Acker asserted that most women spend their lives working in low-paying jobs with few benefits and no future, and the women heading up single-parent families are the poorest in the Nation. Among them are an inordinate number of African American and Hispanic women in a permanent underclass.¹⁷ But, he continued, the plight of the black male is far worse, according to information he gained at a meeting of the national NAACP held in Los Angeles in July 1990 and a New York State NAACP conference in mid-October 1990. "The black male is the only human species who will have a shorter life span in 1990 than in 1980."

At this juncture, Setsuko M. Nishi, then Vice Chairperson of the Committee, remembered research indicating that blacks who attained the age of 65 were found to have a longer life expectancy than do whites reaching the same age. Cryns confirmed her recollection, saying that the phenomenon is known as "the so-called cross-over effect," but it only pertains to those black elders who reach the age of 65. They are "basically the elderly which you would almost say have stainless steel chromosomes to reach that age." While frailty and vulnerability afflict black elders earlier than they do white elders, it is "the super healthy black elders who will reach 65 years of age and older and then also often in better physical condition," Cryns explained, but these make up only a very small group.

A recent *USA Today* article reported that, "Census statistics . . . show blacks account for 16 percent of the centenarian population. Blacks are only 12 percent of the general population."¹⁸ However, at the factfinding meeting Acker emphasized that usually, when one speaks of the African American male, one is speaking of someone who may not even reach age 65,

¹⁷In January 1992 a Washington, D.C., based economist described "a large group of people who have little retirement income other than Social Security, and who, because of a limited earnings record, may find even that benefit to be minimal or nonexistent. . . . These destitute people are most likely to be living alone, to be very old, of minority race, and female." Jack Meyer, president, New Directions for Policy, "Can We Afford Old Age?," *USA Today: the Magazine of the American Scene*, January 1992, p. 23.

¹⁸Margaret L. Usdansky, "Life Past 100: a Joy for Some, Burden for Others," *USA Today*, July 23, 1992, p. 7-A.

"because the African American male has the shortest life span; most of the African American males do not live to 65."¹⁹ He added that economics plays a role in that having employment is necessary since:

A job is not only a paycheck; a job is therapy. [People] who work feel that they are pulling their weight in the boat, that they are doing things to help themselves and their families and not depending on others. So, therefore, being denied a job has a very devastating effect on not only African Americans but everybody.

In this connection, Acker noted that the "Supreme Court has turned back the clock on affirmative action" and the 1990 Federal civil rights bill intended to reverse the Court's decisions was vetoed by the President. Thus, "things [employment opportunities] are worse today than they were 10 years ago," said Acker.²⁰

PHYSICIANS FOR A NATIONAL HEALTH PROGRAM

Dr. Deborah A. Richter, a physician at the Geneva B. Scruggs Health Center and the Mercy Health Center and a local member of Physicians for a National Health Program (PNHP), noted that both centers where she practices largely serve minority populations.²¹ She stated that she believes that health care is a right—a human right—and not just a privilege, and that, of those industrialized nations able to provide health care to all their residents, only the United States and South Africa do not provide a form of universal health care.

As a PNHP member, she described the reasoning behind her organization's proposal for a national health care system, one similar to the Canadian system. The U.S. health care system is wasteful, she claimed, one which involves "too many people doing too many nonessential tasks overload[ing] and suffocat[ing] the system," with large staffs needed to determine what medical treatments are to be paid, how much, and the like. While acknowledging that parts of the existing U.S. system function brilliantly and are unrivaled in the world, she called other parts a "hodge-podge" only rivaled by the most disadvantaged nations. The effect has created a class system in which the best treatment is mostly available only for those who can pay.

¹⁹See also Eve discussion, p. 5 above.

²⁰President Bush signed into law S. 1745, the Civil Rights Act of 1991, (P.L. 102-166) on Nov. 21, 1991. See, for example, Andrew Rosenthal, "Reaffirming Commitment, Bush Signs Rights Bill," *New York Times*, Nov. 22, 1991, p. A-1.

²¹Dr. Richter's remarks in the official transcript are supplemented here by use of her prepared remarks on file in the Eastern Regional Office.

Even more recently, a June 1992 *Washington Post* article focused on persons in the United States who have little or no ability to afford medical care. It reported that "Over any 2-year period, at least a quarter of the population goes without health insurance for one or more months. . . . [L]ack of health insurance may be a wider problem than generally thought."²²

Richter observed that medicare and medicaid are examples of early attempts to help make health care more available and to patch up the hodge-podge system, but they do not provide the full care needed for the elderly because they only cover about 49 percent of their medical expenses. Moreover, according to Dr. Richter, both medicare and medicaid are starting to show signs of strain and "beginning to fail in bigger and bigger ways."

On the other hand, she estimated that it costs "very close to \$69 billion" more to operate the U.S. model than a system would cost under a Canadian-style universal coverage model. She emphasized that the Canadian model is not socialized medicine. It is instead a system mandated at Canada's Federal level, financed by taxes at the Federal level, and administered at the provincial level, or, the level similar to the State level in the United States. She closed by pointing out that in 1989, a U.S. congressional committee argued that "National health care insurance modelled after the Canadian approach would insure all Americans access to high quality, affordable health care," and that in September 1990, a month prior to the factfinding meeting, the *Wall Street Journal* reported that Americans pay 72 percent more than Canadians do for the same amount of service.

Since the October 1990 factfinding meeting in Buffalo, a heightened interest in health care reform—including proposals for a national health care program—has yielded various analyses of current problems afflicting health care in the United States. Agreeing with the proposition that the system is wasteful, Representative Marty Russo, a member of the Congressional House Budget Committee and Ways and Means Committee, recently estimated that, "Twenty-four cents of every dollar spent for health care go for administrative and billing costs. A national financing plan could cut this in half." As Dr. Richter had at the factfinding meeting, Representative Russo spoke favorably of the Canadian model, saying, "Canada spends 11 cents of every dollar on administration under their single-payer system. If the U.S. could reduce administrative costs to that level, it would save \$100,000,000,000 a year."²³

²²Spencer Rich, "Health Care Coverage Gaps Widespread," *Washington Post*, June 25, 1992, p. A-30.

²³Representative Marty Russo, U.S. House of Representatives, "How to End the Health Care Crisis," *USA Today: the Magazine of the American Scene*, March 1992, p. 20.

NEW YORK STATE DEPARTMENT OF HEALTH

William B. Carmello, director of the Bureau of Health Facilities Coordination of the New York State Department of Health, explained that the health department has overall responsibility for ensuring that health care is provided by the appropriate institutions and in appropriate ways under the State's public health law. With regard to long-term care, the health department has a specific responsibility to conduct annual assessments. Both the State's public health law and the medical facilities code require that patients be admitted to long-term care facilities in New York State without discrimination on the bases of race, color, creed, or national origin. At the same time, the health department also applies Title VI of the Federal Civil Rights Act of 1964 in these assessments.²⁴

Unfortunately, noted Carmello, both Title VI and the State's regulations fail to focus on the origin of payment, and, "if there are two individuals attempting to get into a facility and one is 'private pay' and one is medicaid, facilities have the right to admit the private pay [over the medicaid beneficiary.]" Because minorities constitute a significant portion of those on medicaid, they become less readily accepted than those on private pay. This is because a private pay can be expected to pay more than a medicaid beneficiary. Since nursing homes are permitted to accept someone paying more than a medicaid beneficiary, fewer minorities are found in some facilities than in others.

Carmello emphasized that minorities are admitted to long-term care facilities, "but what happens is that they get into county facilities much more readily. . . . So we wind up with underrepresentation or imbalances." He pointed out that medicaid beneficiaries make up between 85 to 90 percent of the long-term admissions in New York City, but less in upstate New York, and "one of our jobs is to ensure that those imbalances are not caused by discriminatory practices."

He also mentioned that the State Public Health Council is convened by the Governor and reports to the commissioner of health. In recent years, the council and the commissioner:

have tried to get through what we called medicaid access regulations. . . . Let's say you have a new facility with 200 beds. That facility would have to admit 75 percent of the medicaid admissions in that area as part of their admissions policy. . . . [For example,] in an area where medicaid is 50 percent, 75 percent of that 50 percent is 37 percent. We would require the new facility to provide initial admissions to medicaid beneficiaries to at least 37 percent of the facility's admissions. . . .

²⁴42 U.S.C. § 2000d (1988). See also U.S. Department of Health and Human Services, *Your Rights Under Title VI of the Civil Rights Act of 1964 in Health and Human Service Programs*, n.d.

Thus, a facility would have to achieve a medicaid admission rate that was “at least 75 percent of the average medicaid admission rate in the long-term care planning area” served by that facility. That area is usually the county in which the facility is located, plus often an adjoining county. The regulations did, however, provide for certain factors that could be considered in modifying the 75 percent. The regulations represented an attempt to mandate medicaid admissions almost on the same level as private admissions. But the regulations were contested in the courts, and the council and the State health department lost. At the time of the first factfinding meeting in October 1990, the case remained on appeal.

However, Carmello recently informed Commission staff that the regulations have been approved and been put into effect. Subject to one exemption, “Title 10: Rules and Regulations” directs in part that:

To ensure that the needs of medicaid patients in an applicant’s service area are met and that such patients have adequate access to appropriate residential health care facilities, beds and services, applicants shall be required to accept and admit at least a reasonable percentage of medicaid patients. . . . Such reasonable percentage of medicaid patient admissions, also referred to herein as the medicaid patient admissions standard, shall be equal to 75 percent of the annual percentage of all residential health care facility admissions, in the long term care planning area in which the applicant facility is located, that are medicaid patients.²⁵

Paula Ciprich, an Advisory Committee member and attorney practicing in Buffalo, asked about the reasons for striking down the proposed regulations. Carmello explained that the Public Health Council had promulgated the regulations pursuant to its authority to consider public need and other pertinent factors when considering applications for new establishments. The private New York State Health Facilities Association contested the regulations in court, challenging the health department’s right to assure that a facility’s patient admission policy provided access to individuals who would be eligible for medicaid. Carmello reported that:

The appellate division third department has affirmed an adverse lower court decision which declared the [State health] department’s medicaid access regulations are invalid as they constitute an affirmative action program that was enacted without expressed legislative authorization and in violation of the Public Health Law.²⁶

Carmello noted that an earlier attempt at legislation was initiated over 10 years ago by

²⁵New York State Department of Health, “Title 10: Rules and Regulations.” See app. B.

²⁶See Blue v. Whalen, 57 A.D. 2d 240, 394 N.Y.S. 2d 290 (1977) construing N.Y. Civ. Rights § 730.2 (McKinney 1992 Supp.).

the State attorney general:

whereby we would prohibit discrimination of any kind in admissions including [on the basis of] payer source or sponsorship. The bill would require a single waiting list be used, because that's the simple solution to it if we can do it. . . . This law was designed to require a first come-first served kind of opportunity.

However, this legislation also failed to be approved, reported Carmello. Since then, the State health department has attempted year after year to win passage of the same legislation but with no success. He observed that a number of long-term care facilities in New York State are profit motivated and have the right to admit private patients over medicaid patients. "Until we are able to overcome those kinds of things, most of us feel it is difficult to prove discrimination."

Carmello also pointed out that, "Frankly, we have had very, very few direct complaints." At the time of the factfinding meeting, he had been bureau director for 13 years, but could recall "less than five complaints, specific complaints that we could follow up on. . . ." This is despite the fact that skilled nursing homes or long-term facilities in the State are required to post "a human rights poster in the corridor, right in the main lobby, and our civil rights poster. . . . I think my office number is on the poster," said Carmello. He voiced surprise that "we have very few specific complaints in this day of litigiousness."

In any case, a family member or representative of someone attempting to be admitted, who believes that the patient is being rejected "not because of their needs but because of their skin color or their religion or whatever else" may call his bureau. Carmello encouraged the Advisory Committee and others at the factfinding meeting to file discrimination complaints with his bureau, "because we do have the right to go after facilities. We do find them deficient. We have the ability to fine them. Medicare and medicaid programs are both set up with the understanding that individuals would have access to those facilities. There are some tools and some weapons we can use if we can get substantial information about discrimination." He also noted that his bureau works closely with the State division of human rights and with the Office for Civil Rights of the U.S. Department of Health and Human Services.²⁷

Carmello mentioned that sometimes a facility is not aware that an admissions practice--such as giving first preference to family members or staff members--may present a problem. That practice might be an innocent method for admitting patients, but it may also turn out "that minorities who may not have staff or family in the [facility] already would be given second

²⁷The State division of human rights and the Federal Office for Civil Rights were both invited to participate in the Dec. 4, 1991, factfinding meeting. The Acting Regional Manager of the Federal office did participate, but the two designated representatives of the State division called to absent themselves on the morning of the meeting.

priority. So we have tried to overcome some of those imbalances." He added that there were two investigations being undertaken in which his bureau was working with a special prosecutor; though he could not discuss any details at the time of the factfinding meeting, he said that employees of facilities had gone to his bureau raising questions about admissions policies where they were working.

Nishi expressed surprise that apparently so few discrimination complaints had been made. However, she noted that under present day practices in many fields "it is very difficult to identify when a person has been discriminated against because there will be a number of other reasons which may do the same thing to disproportionately exclude" minorities. Low minority admissions may reflect highly institutionalized outcomes, she thought, and "It is very difficult to link it to specific intent to exclude." On the other hand, Smith in the *Milbank Quarterly*, has also discussed the differences between the "effect" and the "intent" standards of proof and has explained that "from a population ecology perspective, the conscious 'intent' or choice of an individual facility to discriminate plays an insignificant role." This writer argues that the effect of "patterns of discrimination in geographic access and the economic barriers that help create them . . . is racial discrimination in access."²⁸

Nishi then asked Carmello if there is any systematic way that his bureau monitors admissions at nursing homes to determine if their practices result in equitable admissions. Carmello responded that his bureau's regular survey is taken annually in most cases. Facilities are required to maintain records on "a patient referral" for 18 months. He has investigators who look through the "patient referral" and admission records comparing the most recent year's statistics with the previous year's. His bureau has statistics going back 8 or 10 years. In addition to reviewing records, an investigator tours the facility to determine whether minorities are represented and, if they are, whether room assignments are made without regard to race, color, or creed.

"If we see that a minority patient is being housed with another minority patient and taken care of by minority aides but white patients are treated differently, that is the kind of thing we should be cognizant of."²⁹ In the State's area offices in Albany, Buffalo, New Rochelle, New York City, Rochester, and Syracuse are housed staff—compliance investigators, doctors, nurses, social workers—who make site visits to a facility on a regular basis. He then explained that most admissions to long-term care facilities come from hospitals, and it is the "discharge planning" at the hospitals which is the key.

²⁸"Population Ecology and Racial Integration of Hospitals and Nursing Homes," p. 586.

²⁹Cases in Buffalo hospitals, similar to Carmello's hypothetical example in a nursing home, were found by the New York State Advisory Committee in the early 1960s. See *Buffalo: Health Facilities*, pp. 10, 12-19.

If a patient is ready to leave a hospital, it's quite natural in my opinion, and I think it happens, that if it's a nice Irish Catholic lady leaving, it's very possible that she and her family will be told about facilities where she would feel comfortable; if it's a Jewish person, they might steer [him or her] in a way that would satisfy the family. . . . [and racial and Hispanic] minorities the same way.

On the other hand, there are many who feel that such a process is not correct, and it is not correct, emphasized Carmello. Discharge planning "is a very tough job in this State," and hospitals are being pushed financially to move patients out while at the same time they are being pressed by the State health department and others to do so correctly. Ideally, a discharge planner will take into consideration the needs of the patient and the family, the family's interests, and the location of a facility, and attempt to place the patient in accordance with correct procedures.

Gorey, Cryn's research associate, stated that he was not surprised by the infrequency of discrimination complaints because:

even with all the information that [Dr. Cryns and I] presented, from a methodologically rigorous point of view, no one could make a point that this is a direct effect of race. There is a lot of covariance associated with race that differentiate different groups of people. Take the example [of hospital discharge planning]; we are gaining information about a group of vulnerable elders, those on alternative level of care, ALC. When we take a look at people who are equivalent in their ability to pay, such as medicaid patients, there are other things that differentiate racial groups, and there is a whole host of factors that are relevant.

In terms of access to preventive care at a younger age among the ALC population, there is a profound difference between blacks and whites in the ALC population when the ability to pay is compared. There is also a profound difference between the difficult-to-care-for patient versus the more-easy-to-care-for patient, said Gorey. As for the older African American, there are a number of comorbid conditions and complications which paint an unattractive picture of the patient for a nursing home considering the application of that patient. Thus, even family members seeking admittance for such a patient may not identify race discrimination as the basis for rejection.

Commenting on the ALC population, Carmello reported that he had done "a quick review" of his bureau's ALC statistics out of curiosity as to whether there had been "any skewing towards minorities." For example, one assumption might be that, if there are 1,000 individuals waiting in hospitals to be placed in long-term care facilities throughout a certain region, and, if minorities are not being admitted, "you would think there would be a higher percentage compared to the community, and that's not true. . . . When you throw out all the other variables, it's the same percentage for minorities waiting for ALC as for other individuals."

James Campbell, also of the State health department, added that a review of backlogged ALC patients indicated that, "there is discrimination based on [source of payment]; it is Physical C patients—the light care, low reimbursement patients—who tend to be backlogged. This is what is plaguing the system right now."

Gwendolyn Joseph, of the State health department's Buffalo office, noted that over the previous three Saturdays she had attended a privately sponsored seminar, Erie County Long-term Care Choices, dealing with the alternatives that patients may have. It marked the second year that the seminar was offered, and it was attended by about 250 people each Saturday. On the first Saturday, she counted 10 black participants, and perhaps 5 to 8 on the following Saturdays.

Regarding medicaid admission rates, Joseph stated that there is no way of knowing how many blacks are included within those rates. She knew of no studies that have been done to determine the racial composition of medicaid beneficiaries or what the long-term care catchment areas include in terms of racial makeup or whom a nursing home in Williamsville, a suburb of Buffalo, is serving in comparison to one in Buffalo. She pointed out that it is also important to know what choices families actually have, since most patients hope to be cared for near their own families. Thus, in addition to knowing whether or not blacks are being placed and where they are being placed, it is equally necessary to know what percentage of blacks are on medicaid or eligible for medicaid.

Nishi asked about patient admissions applications and whether the form includes data regarding race and ethnicity. Carmello expressed the wish that Michael Carter of the Office for Civil Rights of the U.S. Department of Health and Human Services had been able to attend the factfinding meeting.³⁰ Carmello has been in touch with Carter over the previous several years regarding a form his bureau had devised called a Hospital and Community Patient Review Instrument (HCPRI). The instrument was meant to be used by all hospitals, doctors' offices, and home health agencies, and it contains two questions referring to racial makeup.

However, members of some organizations have suggested that his bureau should not ask such questions. Carmello's response to them has been that his bureau would be unable to do its job if it does not have the statistics generated by the questions. Carmello explained that—if his bureau does not know how many respondents have submitted HCPRI's and what the percentages are of minority referrals—it would be impossible to determine what each long-term care facility is doing. With HCPRI data, his bureau can look at the number of referrals and see that

³⁰Carter had been scheduled to participate in the October 1990 factfinding meeting, but due to unanticipated budget complications became unable to do so. As reported below, he did attend the December 1991 factfinding meeting in New York City.

"if there are 100 referrals of minorities but no placements [of minorities], that is obviously an alert to us to work with that facility or hospital and find out why minorities are not getting in. . . ." Although the HCPRI was under review at the time of the October 1990 factfinding meeting, Carmello's bureau was using it, and it did contain questions asking for racial data.

Representing the Commission's Regional Office in Washington, D.C., Tino Calabria asked if the data collected by Carmello's bureau "indicate by race and ethnicity those who apply for admission to nursing homes." Carmello responded that his bureau collects data on who is admitted to a nursing home but not on who is denied admission.

When we gather our statistics of those who are in a facility, we get it by payer source and we get it by racial composition so that we can tell, of the 100,000 individuals in New York State that are in long-term care right now, how many are black, how many are Hispanic, with a breakdown of oriental. . . . In fact, the Feds break it down to Alaskans or Aleuts, even Samoans. . . . What we do not know is how many applied.

Carmello also did not know of any other State that may be attempting to study the kind of issue under discussion. However, he believed that "New York State is probably ahead in this area where we require a nursing home to keep [data on] every possible referral and because this HCPRI form has to be [submitted] by discharge planners on a regular basis." He said that a discharge planner might send in the form on the same patient five times in one period before the patient is finally admitted to a facility. All of the facilities maintain thousands of these documents on who is admitted. However, the missing data are the statistics on how many minorities applied for admission, whether admitted or not. Even Title VI data which is collected for the Federal Government does not yield information on payer or sponsorship.

At the same time, Carmello pointed out that, even if those missing data were to become available and if it were also shown by race or ethnicity how many applicants sought admission with or without success, there remain "so many variables and so many clever ways that individuals or organizations can keep [applicants] out. They can say we cannot handle a patient who needs a ventilator or something else exotic. So there are ways of getting around the system." He said that the limited data available on admissions are put into a quarterly report sent to the State department of social services, which then sends it to the Federal Office for Civil Rights.

James S. Cunningham, the Commission's Assistant Staff Director for Civil Rights Evaluation, asked whether any State agency or perhaps any private organizations had considered the use of "testers" to uncover discrimination. Carmello responded that over the years he had advocated that approach with the State health department working through another agency such as the State attorney general's office or a special prosecutor. If the health department were di-

rectly involved, he thought that it could be viewed as entrapment. In any event, he believed that testers should be tried in a few facilities where there has been "the impression that their admissions policies are questionable." One method would be to try to gain admissions for a minority patient at the same time as for a white patient on medicaid, making all other circumstances the same. Although he thought that other agencies were using testers in their programs, the State health department has not, said Carmello.

Cunningham then requested clarification on Carmello's opening remarks about medicaid recipients being turned away from facilities in favor of applicants able to pay privately. "That is what happens," Carmello responded. "On a given day, if you were medicaid and I were private and we both applied to a facility, that facility has the right to take the private patient," a person paying perhaps \$50 more. When Cunningham asked if the facilities were occupied to capacity, Carmello explained that long-term care in New York State functions on a franchise basis with the State health department controlling the licensing of the facilities. He believed that:

if we open it up like any other business, it would alter things. But right now we restrict how many facilities and how many beds there are going to be, and most facilities have waiting lists. I mean it's a great business. People complain about it, but individuals are knocking down the doors to buy nursing homes.

Cox inquired whether the time consumed in processing medicaid applications has a bearing on the decision to accept a private payer over a medicaid applicant. Carmello said that such might be possible, but any medicaid patient in a hospital has already been established as eligible, and the process may not take any longer for that patient. He did acknowledge another possibility, that the status of an applicant whose medicaid eligibility was still pending might deter a facility from accepting that patient.

Joseph stated that she had worked on nursing home admissions and observed that, "it is up to the nursing homes whether or not they are willing to take a medicaid-pending patient. . . . Most of them will if they have a bed available." The seminar that she had attended the previous Saturday involved several nursing home administrators, and "the not-for-profit administrators had to admit that in order to accommodate patients that are medicaid, that is, patients who are poor and indigent, [those administrators] had to have a percentage of 'private pays.' In fact, they said that a lot of these patients are balanced on the backs of the 'private pays.'" In short, for the same reason even the not-for-profit nursing homes had to admit a certain percentage of "private pays," she suggested.

Then Advisory Committee member Walter Y. Oi asked in what way those wishing to open new nursing homes may be prevented from doing so. Carmello replied that the State's Public Health Law 2800 requires approval by the State Public Health Council. The qualifications

reviewed by the council include “need, character and competence, and financial feasibility, and need is the key.” To open a 200-bed facility in certain areas, for example, one must demonstrate statistically that there is an unmet need. Oi wondered, “Why is that requirement there? We don’t ask McDonald’s to show a need before it opens [a restaurant.]”

Carmello explained that New York State, like many other States, has a franchise system, and apparently there is a belief that if the State allowed 100 more nursing homes to open, medicaid and medicare costs would “skyrocket.” The reasoning may be similar to that regarding physicians; “there are some who feel that the more doctors, the more expensive it is going to be,” said Carmello, acknowledging that “I’m not sure, but I never quite understood that economic theory.”

Carmello asked Richter if New York State restricts the number of physicians practicing in the State. She replied that the State restricts the number of medical schools. Suggesting that such a restriction may then result in a restriction on the number of physicians, Carmello added that, “So we are not saying that if we have more doctors, everything would be great because [medical care] would be cheaper and more available.” Richter agreed, speculating that “The more doctors there are, the more they perceive that they have to maintain their income. So they provide more services, and, for example, a physician who has a medicaid patient, in order to make ends meet will have the patient come back again and again.”

Regarding possible parallels between the cost of care as related to the number of doctors available, alluded to by Carmello, the July 1992 lead story in *Consumer Reports* indicated that:

Actuarial studies have shown that in areas with the greatest supply of physicians, people simply go to the doctor more often. . . . The phenomenon of induced demand applies to hospitals, too. . . . Physicians almost unconsciously refer their patients to the hospital if space is available, stopping only when the local hospitals’ capacity is nearly used up.³¹

Moreover, a September 1992 article in the *National Journal* indicated that in general, “Too many physicians are being trained as specialists and not enough as generalists. As a result, the nation’s health care system emphasizes high-cost, high technology medicine at the expense of basic and preventive care.”³²

On the related question about limits on the number of nursing home beds, the author of *The Nursing Home Handbook*, a 1989 volume in the American Association of Retired Persons

³¹“Wasted Health-Care Dollars,” *Consumer Reports*, July 1992, p. 39.

³²Julie Kosterlitz, “Wanted: GPs,” *National Journal*, Sept. 5, 1992, p. 2011.

(AARP) book series, has asserted that, "one reason for this 'tight supply' indicator is that many States have taken steps to limit the number of available beds for medicaid patients in an effort to control expenses."³³ More recently, in an August 20, 1992, article a *New York Times* reporter similarly observed that, "some States have halted nursing home construction to control rising medicaid costs for the care of indigent people in nursing homes."³⁴

At the October 1990 factfinding meeting Campbell said about the construction of nursing homes, that the State Public Health Council employs a "certificate of need" process to respond to a Federal health planning regulation. He pointed out that beyond the certificate of need there are other requirements on financial arrangements that must be met such as "securing HUD mortgages and other types of environmental impact studies." These various steps have lengthened the process considerably, he said.

Noting that there was an inventory of approximately 10,500 beds in the eight counties of western New York, Campbell stated that there were over 1,000 more approved beds awaiting construction in western New York. But he emphasized that those beds "have been waiting anywhere from a year to 2 years for construction. . . . It used to be 18 months to 2 years to build a nursing home, some 10 years ago, but now, at least a 3-year to 4-year construction period after the facility has received approval." He knew of one facility whose structure was not approved because of environmental problems; it had been delayed over 18 months.

At a time when western New York State is 1,000 beds short, 1,000 beds have been approved, but they exist only on paper, said Campbell. The shortage is aggravated by the fact that a reduction in the turnover in beds has begun. Patients in long-term care facilities tend to occupy beds longer because they are living longer. Given the shortage in vacant beds, "what is going to happen is that the private pay patient will always get the bed." Campbell added that, "The Blue v. Whalen decision of some 10 years ago, I believe, knocked out our ability to take action based on financial sponsorship. We lost in court."³⁵

Nishi asked if facilities under religious sponsorship must abide by the State's requirement of nondiscrimination. Carmello answered that they do, adding that, when a proposed facility is reviewed by the Public Health Council, the sponsor's original papers are examined, and, if those papers indicate religious sponsorship, then that sponsor has a right to show preference to

³³Jo Horne, *The Nursing Home Handbook*, (Glenview, Il.: Scott, Foresman and Company, 1989) (hereafter cited as *The Nursing Home Handbook*), p. 30. See also, deputy speaker Eve's discussion, p. 6.

³⁴Carol Lawson, "Day Care Offers a Better Life to the Old and Ill," *New York Times*, Aug. 20, 1992, p. C-10 (hereafter cited as "Day Care Offers a Better Life. . . .")

³⁵See above note 25.

the adherents of its religion. "So we do allow it, and we do enforce the same rules, but you can give preferential treatment if it is built into your original charter." Carmello also mentioned that fraternal organizations, such as the Masons, sponsor facilities in New York State, and the key question is: do their facilities discriminate? "If they do not, the organization which is the sponsor of the long-term facility can carry out the mandates for long-term care."

ERIE COUNTY DEPARTMENT OF SOCIAL SERVICES

Robert A. Mendez, commissioner of the Erie County department of social services, said that the county's department of senior services played an important role in the determination of needs among the noninstitutionalized black elderly in the area. Its 1988 report was done in conjunction with SUNY Buffalo and that school's center for the study of aging. An update of the report was funded by the New York State African American Institute in Albany, and it was entitled *The Assessment of Health and Social Service Needs of Older African American Residents of New York State*. The update covers statewide the issues that his department had earlier identified for Erie County.

Mendez described the broad array and wide network of services his agency sponsors on a contract basis. They include transportation, escort service, case management, case assistance, errand and chore and friendly visiting, home care, congregate dining, meals-on-wheels, and information on access assistance. In the district that contains the primary concentration of minority elders in Erie County, one-fifth of all his agency's services goes to those minority elderly. His agency also frequently sponsors public factfinding meetings which have further contributed to its knowledge of what elders both want and need.

From all this experience, his agency is convinced that, "at home is where most seniors wish to be." Moreover, "there is another underlying truth to be understood: there simply are not enough long-term care beds in Erie County to handle the needs of those both eligible for, and assessed at, the level of need." As for individuals in the lower economic groups, Mendez said that they have the most difficulty in gaining access to long-term care beds. He asserted that:

The medicaid population has placed a great demand on nursing home care beds. The situation has been made more difficult by the fact that many elders have lost their support systems. Families have moved away, spouses and elders become dependent on those of us in public service and community agencies to act as their voices. . . . If we are to solve some of the problems . . . we have to come to grips with the realities of joining the community care system with a long-term care institutional system. We have to talk to each other.

Mendez pointed out that the only formal link between these two systems is through the ombudsman program of the New York State office for the aging, which offers volunteers who serve as patient advocates. He believed that such an arrangement was adequate for those elderly who are already in a nursing home. But for those elderly still in the community whose views of institutional care are affected by common myths, it is necessary to provide factfinding meetings on institutional living so that their fear of what is really an extension of community living can be alleviated.

Again, in the public sector, Mendez suggested that there needs to be a great deal of improvement in the link between his agency and Carmello's. The primary focus of Mendez' agency is on "encouraging and assisting seniors to be able to live independently as long as possible before they need that next level of care, and that is one of the areas that we feel does need to be improved: how do we go from point A to point B?" that is, from independent living to nursing home care. Carmello's response to Mendez' question was that the State health department maintains "an ongoing dialogue in many ways with the State office for the aging" and, assuming that Mendez' agency "works for the State office for the aging," Carmello said that there is a connection at some level there.

Returning to the availability of nursing home beds, Oi observed that the size of the elderly population 70 years and older was growing at a quickening pace and that, even if the already approved 1,000 beds were soon to materialize, a shortage would continue. Campbell said he could not estimate what the shortage would be, since he did not know what the turnover rate was. On the other hand, he thought that the 1,000 beds represent "a start, and there will undoubtedly be other alternatives beyond that." For example, if "supportive housing" offering some health care were built, that would "take the pressure off the nursing home beds."

However, there has been little interest in supportive housing, said Campbell, despite the fact that supportive housing costs would be about \$1,500 to \$1,600 a month while moving a person to the "health related level" is about \$2,000 a month, and a skilled nursing facility is about \$3,000 a month.³⁶ Because supportive housing is not recognized by medicaid or medicare as entitled to reimbursement, many individuals are channelled to the more costly arrangements. The present situation is such that an older person is moved "from the \$650 a month in supplemental security income in a domiciliary level of care up to a \$3,000 a month nursing home bed." He also pointed out that the State health department "had just relicensed all its beds as nursing home beds." Carmello agreed, noting, too, that the Federal Government has eliminated the category of intermediate care facilities, and now "everything is a nursing home or a skilled nursing facility."

³⁶See also discussion by Carl S. Young and March 1992 cost estimate, p. 41, below.

Nishi explained that Hispanic and Asian American organizations were invited to the first factfinding meeting but were unable to attend. She asked Carmello whether he could offer any observations about possible inequities or special obstacles that elders in those communities encounter. Carmello replied that his bureau does not do any analysis or longitudinal studies of Hispanics or Asian Americans. But he ventured his personal opinion that there may be a much lower percentage of Asian American elders in long-term care facilities than is their percentage in their community. He also believed that their smaller presence in nursing homes related to cultural factors and familial ties. He thought much the same held true for Hispanics, but further noted that many Hispanics in New York City seem to return to Puerto Rico upon reaching a more advanced age.

Gorey then reminded the Advisory Committee about the point he stressed earlier regarding "equitable access and whether the industry is doing a good job with population proportion as the criterion." He noted that an assumption underlying the concept of population proportion is that all older people constitute a homogeneous group and that the need is the same among all the different cultural and racial groups. He stated that his research in New York State and his review of research around the Nation both indicate that such an assumption is erroneous. Consequently what must be achieved, Gorey argued, is a need-based system offering long-term care, just as Richter had earlier advocated a need-based system of medical care.

HHS OFFICE FOR CIVIL RIGHTS

In December 1991 in Manhattan, Joseph N. Kennedy, the Acting Regional Manager for the Region II Office FOR Civil Rights (OCR) of the U.S. Department of Health and Human Services, was the opening panelist at the Committee's followup factfinding meeting. He prefaced his remarks by generally observing that "if you are a poor African American or a poor Hispanic, if you are not of the same native land, if you do not practice the same religion, your request for the 'benefits' of being an American and your civil rights may be denied."³⁷ He then described OCR's monitoring of the recipients of Federal financial assistance. OCR's mission is to determine if those recipients comply with the applicable civil rights laws.

Kennedy said that the Nursing Home Act of 1964, section 504 of the Rehabilitation Act of 1973, the Community Service Assurance of the Hill-Burton Act, and the Omnibus Reconciliation Act of 1982 each provides protection for the disabled and the elderly, while OCR also safeguards the rights of minorities through Title VI of the Civil Rights Act of 1964. OCR's 10 regional offices cover the United States through a staff of 325, while OCR/Region II fields a staff

³⁷Kennedy's remarks in the official transcript are supplemented here by use of his prepared remarks on file in the Eastern Regional Office.

of 19, hardly sufficient to monitor all the nursing homes on a one-to-one basis, according to Kennedy.

Nevertheless, the OCR/Region II staff conducted “more than 2,100 compliance actions” during the previous 5 years. A number of these were pregrant reviews in which OCR supplied instructions and technical assistance while obtaining commitments on compliance from recipients even before the recipient obtains a grant or clearance to participate in the medicaid or medicare programs. Despite having engaged in over 2,100 compliance actions in the region, Kennedy believed that the level of compliance review activity was still “less than enough to have a deterrent influence on the more than 585 nursing homes we did not contact during the year.” He further indicated that were it not for the pregrant reviews which OCR initiates, “Title VI monitoring would be virtually absent.”

However effective OCR may be through its pregrant reviews, its overall effectiveness is in part determined by the general public and the public’s willingness to communicate with OCR and file complaints. He later noted that there were fewer than 10 Title VI complaints filed against nursing homes and health-related agencies in the previous 5 years. He also asserted that “We do not believe that the numbers reflect the level of discrimination” and “we have known for some time that disproportionately fewer minorities are admitted to nursing homes.” Some reasons why this is so include: the economic disadvantages affecting minorities, the ineligibility for medicaid among the working poor who may earn just enough money to be considered as “self-pay,” the lack of general attention to health care resulting in less contact with counselors and social service administrators, and the scarcity of health care professionals and facilities in poor communities.

On the other hand, Kennedy stated that it is “a common myth that minorities, that is, African Americans and Hispanics, take care of their own.”³⁸ He depicted the notion as “nothing more than a rationalization of historically discriminatory behavior patterns.” He also said that African Americans and Hispanics are two groups disproportionately represented in the ranks of the poor and, as a consequence, not in the elder care network. At the same time, divestiture or signing over one’s assets to gain entry to a nursing home is a repulsive thought to an African American—someone who may be unaware of the strategies that the wealthy use to avoid surrendering everything they own to enter a nursing home.

Regarding divestiture, a founder of the National Academy of Elder Law Attorneys recently writing in the *Washington Post* advised the spouse of an applicant for nursing home admission that:

³⁸See discussion by deputy speaker Eve, p. 7 above, and by Carmello, p. 26, on minority communities’ caring for their own.

Nothing pays for long-term care except cash or medicaid, and then only after you have exhausted your cash. Medicare and private health insurance like Blue Cross/Blue Shield will not pay. . . . Medicaid requires that all assets be spent down to about \$2,000. Everything except your home is included. . . . Medicaid treats income differently, however; it is kept separate. The at-home spouse is not required to contribute any of her income toward a spouse's nursing home bills.³⁹

This last stipulation seems to be in keeping with a recommendation appearing in the *Final Report: the 1981 White House Conference on Aging*:

The current level of living of the spouse of a person in need of long-term care should not be lowered by requirements that force the noninstitutionalized person to contribute excessive amounts of money to pay for the costs of care for his or her disabled spouse.⁴⁰

By early 1990, however, attorneys writing in the AARP's bimonthly magazine, *Modern Maturity*, counseled that "Assets belonging solely to the at-home spouse are no longer totally protected as they were in some States under prior law."⁴¹ In fact, a different source, writing in a May 1988 issue of *Consumer Reports*, described a spouse becoming impoverished in 9 months before medicaid began supporting her husband's nursing home care.⁴² In 1991, a third source wrote that "the unfortunate effect of the medicaid income and assets limits has been to force more than a few couples to divorce for solely economic reasons. . . ."; this source suggested that "if all other methods of transferring or otherwise protecting assets are unavailable, you may at least want to consider the alternative of divorce."⁴³

Kennedy also found alarming the practices of some hospitals and referral sources. Their behavior:

reinforces the perception of minorities that they are relegated to less desirable homes. The result is a system that bars minority consumers from the better facilities and an understanding that they will end up in substandard care. The truth is that minorities have no choices. Seeing a homeless elderly person is a

³⁹Harley Gordon, founder, National Academy of Elder Law Attorneys, "Seniors: Your Retirement Dollar," in the "Family & Retirement" section, *Washington Post*, Apr. 29, 1992, p. 18 (hereafter cited as "Seniors: Your Retirement Dollar").

⁴⁰*Final Report: the 1981 White House Conference on Aging*, vol. 3, n.d., p. 115.

⁴¹M. Garey Eakes and Ron M. Landsman, "Medicaid, Money, and You: New Rules Govern How Much You Keep When Your Spouse Enters a Nursing Home," *Modern Maturity*, February-March 1990, p. 87.

⁴²"Must You Die Poor?," *Consumer Reports*, May 1988, p. 310.

⁴³*Elder Care*, p. 7/14.

stark reminder that many of those needing nursing care are not self-sufficient, and they are not being taken care of by their own.

Kennedy further pointed out that everyone—African Americans, Hispanics, and whites—“all opt for better conditions when there are choices,” and access to family and convenience is critical. At the same time, the location can also influence a nursing home’s ability to employ a stable and competent staff. He further noted that, if a facility caters predominantly to medicaid patients, it is less able to compete for top quality professional services and is less likely to attract stable employees. Almost 10 years ago, such a possible pattern was noted by a specialist who wrote that “It is widely alleged that nursing homes, particularly the ICFs [intermediate care facilities], are understaffed, poorly managed and offer an extremely low quality of nutritional, medical, sanitary, and protective care.”⁴⁴ More specifically, the August 1992 issue of *NBA: National Bar Association Magazine* included an article that asserted that “Elderly beneficiaries of medicaid will discover, as have other medicaid recipients, that the services provided to them may be inferior because ‘the average medicaid physician is less qualified to practice medicine than other practitioners.’”⁴⁵

Regarding data on race, Kennedy pointed out, “Routine statistics on the number of nursing homes residents by race and ethnicities are not available. As a general rule, the Department of Health and Human Services does not collect these data.” On the other hand, he indicated that State agencies on aging may have such information on nursing home residents, since many nursing homes have agreed to maintain the data as a condition of receiving medicaid certification. At the same time, he decried the reality that “Increasingly nursing homes have not maintained applicant flow data.”

Another factor relates to ethnicity and religion, said Kennedy.

While a nursing home that receives Federal financial assistance is prohibited from restricting admission, . . . Protestant is less likely to attend a home identified as a Catholic institution. Moreover, a Jewish home for the elderly will more likely attract Jewish residents than a Catholic Hispanic or black who may not be of the Jewish faith.⁴⁶

Kennedy noted that other critical factors include services for specific disabilities requiring oxygen therapy, renal dialysis, and tracheotomy and tube feedings. HIV individuals and others

⁴⁴Joan M. Krauskopf, *Advocacy for the Aging* (St. Paul, Minn.: West Publishing Co., 1983), p. 467.

⁴⁵Gerald Roberson, Esq., “The Continuing Health Care Dilemma of Elderly Americans,” *NBA: National Bar Association Magazine*, August 1992, p. 12.

⁴⁶See also discussions above by deputy speaker Eve, p. 7, and Carmello, pp. 22 and 24.

generally thought of as “needing heavy care” become of concern to nursing homes, and such disabilities “magnify the impact of discriminatory policies and practices. If anything, nursing homes may use these as a pretext to discrimination.”

When charges of discriminatory denial of admission are verified, said Kennedy, the remedies are to rectify the individual harm and take actions to preclude discrimination from happening again. The remedy may be developed as a result of an OCR compliance review or the result of a complaint investigation. In either event, OCR monitors the facility’s performance until it is assured that compliance has been achieved. To become more effective in safeguarding the care of the minority elderly, OCR must continue its seminars and workshops, increase the number of compliance activities related to nursing homes, improve internal processing times, maintain and improve dialogue with the community, and develop referral networks with State agencies to increase Federal involvement where noncompliance is suspected. OCR is rising to meet the challenge through a number of actions:

expanding outreach efforts to better educate the public, developing more efficient compliance monitoring strategies, developing a training institute to improve staff skills, restructuring [OCR] to improve the ratio of investigations to staff members, and increasing the volume of nursing home compliance reviews.

Beyond that, continued Kennedy, a strategy based on a “tripart responsibility” is needed that would unite the forces of the beneficiaries, the recipients or private sector, and government. Each must make its contribution to the unending battle of repudiating discrimination wherever it is found.” He closed by asserting that “the present challenges we face are not insurmountable, but the road to the correct level of vigilance is not easily traveled. We must deal with the peculiar history and strengths of the minority consumer so that when [Department Secretary Lewis] Sullivan’s realization of a longer minority life span is attained, the vestiges of discrimination will have been eliminated.”

GREATER NEW YORK HOSPITAL ASSOCIATION

Dr. Lauren G. Pete, the director of the long-term care division of the Greater New York Hospital Association, explained that her association represents over 17,000 beds in nonprofit hospitals and nursing homes in the metropolitan New York City area including Nassau and Westchester Counties. She responded to Kennedy’s comments, saying:

I would like to see some of the statistics or some of the figures upon which you base your generalizations. . . . I have a problem with dealing with some of your comments when you start off by saying that nursing homes do not have statistics on the racial breakdown on residents in their facilities. If that is true, how can we

determine whether or not discrimination is actually going on. . . . If we do not know who is in the homes, how do we know someone is being discriminated against?

Kennedy interjected that "I did not say that nursing homes do not keep statistics . . . [but] that in many instances, they are not maintaining applicant flow statistics, which is the number of people who actually apply for services or entry to the nursing home." He acknowledged that nursing homes do maintain data by race and gender of the residents within the nursing home itself.

Pete reiterated that she did not understand how Kennedy could have determined that discrimination is taking place at long-term care facilities. Moreover, she said that she knew of no nursing homes that have been told by their attorneys not to keep data and that she was concerned that "we don't learn from generalizations without making some kind of attempt to be a little more specific." She also voiced concern about Kennedy's assertion that nursing homes may be using the need for services or equipment like deventilators to screen out minorities, and hoped that some documentation or support for his statements could be obtained.

Nishi expressed astonishment that there had only been 10 complaints over 5 years and asked what the outcomes were. Michael R. Carter, the OCR Investigation Division's Branch Chief, explained that a complaint may start as a phone call that subsequently becomes a detailed letter. The 10 complaints referred to earlier came from the entire Region II jurisdiction of New York, New Jersey, Puerto Rico, and the Virgin Islands and had to do with admissions. In the same 5-year period, at least several dozen nursing home employment complaints were also processed. Both OCR and other agencies of New York State may become jointly involved in such investigations.

As to the admissions complaints, they have all been resolved, said Carter. Some resolutions "addressed policies based on race, color, or handicap. Other cases may have involved a series of procedural violations, such as several areas under section 5 or 6 of the Rehabilitation Act which requires certain kinds of services to the sensory impaired." The facilities came into voluntary compliance in most cases once OCR entered into an agreement with them on a corrective action plan to rectify the specific complaint as well as to modify any policies or practices that needed changing.

Nishi then inquired as to the factors at work which kept down the number of complaints on admissions. Carter replied that first of all in many cases it related to an absence of knowledge on the part of the entire beneficiary population. This was despite the fact that from 1983 to 1987 OCR conducted a number of workshops, conferences, and seminars aimed at both the population of beneficiaries and the recipients of Federal assistance. The goal was to increase

knowledge on both sides of their rights and responsibilities, continued Carter. Complaints were generated, but most of them dealt with employment rather than services.

Committee member and moderator Cox suggested that State government each year expends resources on annual inspections of nursing homes and yet "the State has never once conducted a thorough investigation of civil rights violations, has never once conducted enforcement action, and has never once actually found any New York State nursing home in noncompliance with the 1964 Civil Rights Act" despite the fact that millions of dollars are paid over the years to conduct annual surveillance reports. He asked Kennedy and Carter whether that disturbed them.

Kennedy replied that it is a concern, and "one of the ways in which we try to address that concern is to begin to share the responsibilities [for civil rights enforcement] with the State agencies." However, having worked in other multistate Federal regions, he added that, "Quite frankly, the performance of the States has not been that good and for that reason, we have to rely upon the third component which is the beneficiaries themselves coming to us to tell us. Because for all the surveys that are done, I have not had anything referred to me, and I have worked in several regions."

Before Kennedy and Carter departed, Carter added that the number of complaints has been low in Region II "for the past 5 years and perhaps for a longer period of time." Nevertheless, OCR/Region II was successful during the same period in conducting "project reviews whereby we identify maybe 25 or 35 nursing homes around the region, primarily in New York and New Jersey, and we target those nursing homes for what we call single issue reviews where we have found patterns of problems," most of them relating to section 504. He reported that "in over 90 percent of the project reviews we have taken action."

NEW YORK STATE OFFICE FOR THE AGING

Carmen Vinales Cunningham, the director of Affirmative Action Programs for the New York State Office for the Aging, said that State office director Jane G. Gould, who had been invited to participate in the October 1990 factfinding meeting, was again unable to attend, but welcomed the opportunity to have the office represented during this discussion. Cunningham explained that the State office is designated by the U.S. Administration on Aging to advocate "for the development, coordination, and administration of a comprehensive delivery system for the over 3 million elderly New Yorkers."

With primary Federal funding from the Older Americans Act⁴⁷ and with State and local funding, the State office oversees 59 local offices for the aging, including 2 on Indian reservations. She said that an important responsibility of the State office is to "promote and advocate for long-term care services" and it is committed to "expand community and home based long-term care services designed to prevent the need for the institutionalization of an elderly person."

Although the State office has only "limited programmatic or policy authority in nursing homes or other custodial long-term shelters," it administers an ombudsman program affording the residents of long-term care facilities and their families an opportunity to discuss problems and develop solutions. In this way, the State office and the 39 local ombudsman program sponsors advocate for nursing home residents. Ombudsman personnel "receive, investigate, and resolve a wide range of concerns and complaints about the conditions in long-term care facilities." Cunningham also noted that a possible policy area for the State office to consider is the development of an appeals mechanism to handle nursing home denials which would work in close cooperation with the ombudsman programs.

Regarding racial or ethnic statistics on the New York State nursing home population, Cunningham said that such data are not compiled by the State office. She noted, however, that the data might be obtained from the State department of health, which has:

a Patient Review Instrument [PRI] for nursing facility residents developed as a tool for determining nursing home case reimbursements. This is the only document to provide a computerized profile of recipient characterization.

She believed that the PRI has been examined by the State division of human rights regarding the legality of collecting ethnic data and the use of the PRI at a nursing home before the patient actually appears for a bed; the State division does "not want [the PRI] which identifies ethnicity to be at the nursing home before the person shows up." At any rate, Cunningham also observed that, "lack of constant data hampers policy development for the long-term care system."

Cunningham then explained that economic and racial discrimination affecting services for the elderly—particularly long-term care services which can be more needed by many minority elderly and more costly—has major policy implications for government agencies in New York. This is because there are a variety of crosscutting policy and administrative issues among the State agencies involved. The State department of health has the primary regulatory authority over the administration of hospitals and nursing homes, including the admissions process.

⁴⁷42 U.S.C. § 30001 et seq. (1988).

Meanwhile, the State department of social services is responsible for overseeing implementation of the medicaid program which covers a significant portion of the total patient health care expenses incurred in the hospitals and nursing homes around the State, said Cunningham. "Out of necessity, the medicaid program has become and remains the primary vehicle to meet long-term care needs. As the recipient of Federal medicaid funds, the department of social services has the definitive civil rights enforcement obligations required by Title VI of the Civil Rights Act of 1964." She added that the Older Americans Act mandates the targeting of services to those in greatest social and economic need with particular attention to low-income minorities, and that this is a priority at every level of the aging network, Federal, State, and local.

Cunningham explained that among the many steps taken to increase access and information for the minority elderly was the establishment of a statewide committee on minority participation. The 15-member body includes representatives from across the State, of differing cultural, ethnic, and work backgrounds. The committee is to assist director Gould of the State office for aging in identifying barriers and devising strategies to overcome barriers to equal access for the minority elderly. For example, one member is an older Native American who informed the statewide committee that Native Americans age 45 and over exhibit many health characteristics of the white population 65 and over; this member hoped that Native Americans could gain access to nursing home care through the establishment of a home on her upstate reservation.

Cunningham also pointed out that the State office was directly involved in the New York State Nursing Home Task Force which issued a report in June 1986. The task force consisted of representatives from the State department of health, the State office for the aging, the State division of human rights, and Friends and Relatives of the Institutionalized Elderly (FRIA). It had been formed as a result of a report issued in 1984 by FRIA which had alleged racial discrimination by hospital discharge workers and other hospital personnel leading to segregation in nursing homes in New York City.

The task force's report included specific recommendations regarding hospital discharge planning and admissions to nursing homes. Moreover, it recommended the establishment of a data base on referrals and admissions to document if systematic racial discrimination affected decisions on nursing home admissions. Later, the task force report revealed, in fact, that minority representation in nursing care facilities was low.

From subsequent studies and reports, said Cunningham, it is clear that minorities have a higher prevalence of chronic disease and a higher level of impairment than whites of the same age and, therefore, the likelihood for the need for long-term care may be higher as well. And yet, the State office for aging, as a member of the task force, also became aware that rep-

resentation of the minority elderly in nursing homes was disproportionately low. Therefore, the State office has supported bills and legislative proposals intended to correct the problems. These problems with access are varied and well-documented, and, holding aside problems stemming from discrimination, Cunningham focused on some systemic problems of an institutional nature barring the minority elderly from access to health and social services.

They included: the perception of health care providers that all minority families tend to, or prefer to, take care of their own even in the neediest of cases; the lack of awareness by many minority elderly of existing long-term care services and how to navigate successfully through bureaucracies and entitlement programs; and inadequate or lack of communication between minority elderly or persons acting on their behalf on the one hand and the health care providers on the other hand. Under such circumstances, cultural and socioeconomic differences further lead to inadequate access, continued Cunningham, and the experience or memories of government agencies which minority elders often have do not benefit them in acquiring the services they currently need. Some also have culturally based fears regarding divulging personal information. As to filing complaints, her personal opinion was that "elderly people tend not to want to complain and not to file complaints. That is very realistic of the low numbers [mentioned by OCR]."

Issues of racial disparities in medical coverage were being examined by the National Senior Citizens Law centers and other advocate groups across the country, said Cunningham. She then observed that lawsuits in Tennessee and Pennsylvania have sparked a reaction moving many States to determine to what extent State policies that allow medicaid discrimination violate the civil rights law as well as the medicaid statute. She described the significance of Linton v. Commissioner of Health and Environment⁴⁸ as yielding a finding that discrimination by health care providers against medicaid patients has a disparate impact on minorities and that "there is a definite correlation between poverty levels, ethnicity, and medicaid status."

But Cunningham also pointed out that New York State—unlike Tennessee—does not allow limited bed certification, the catalyst in Linton.⁴⁹ She expected that the New York State office for aging would continue to follow developments in this suit and in suits surfacing elsewhere. In Pennsylvania, for example, part of the justification for the alleged discrimination

⁴⁸See supra note 1.

⁴⁹See Peter Mellette, "Linton Case Leaves State Medicaid Bed Certification Policies in Doubt," *Long Term Care Management* (Washington, D.C.: Faulkner & Gray's Healthcare Information Center, Nov. 29, 1990), pp. 4-6, and "Court Rules Medicaid Discrimination Violates the 1964 Civil Rights Act: Tennessee Agrees to End Limited Bed Certification," *Quality Care Advocate*, National Citizens Coalition for Nursing Home Reform (Washington, D.C.), May/June 1990, p. 1.

there was that "the segregating nursing homes are, in fact, religious."⁵⁰

Cunningham reported that Governor Cuomo, in his 1991 "State of the State" message, directed the State office to examine the feasibility of implementing a program known as Managed Access to Aging Services (MAAS). This program would establish a single point of entry to long-term care for the State's elderly. Its key features include the consolidation of responsibility and authority for managing the elderly's access to long-term care services and placing the responsibility and authority in the State office. It would also designate local long-term care case management agencies with the responsibility for assessing need for such care, determining the most cost effective method for responding to those needs, authorizing last resort public payment for needed services, and continuing case management to monitor the provision of services and make adjustment in care plans as appropriate.

Cunningham described the MAAS proposal as representing basic change in long-term care responsibilities by establishing clear accountability for the first time. Increasing access for minorities will be factored into MAAS, since cultural diversity issues will be an integral part of program planning and training for newly developed MAAS entities or agencies. It will also provide a data base for referrals to nursing home facilities.

FRIENDS AND RELATIVES OF INSTITUTIONALIZED AGING (FRIA)

Jeffrey Ambers, the executive director of Friends and Relatives of the Institutionalized Aging, whose 1984 report had been referred to by Cunningham as having supplied allegations about discrimination in nursing homes, explained to the Advisory Committee that in the State department of health "are six areas that have the responsibility for monitoring Title VI compliance and there are supposed to be six civil rights compliance officers." He said that three of the positions have been "vacant for a long time, and the State is threatening to do away with the other three positions." Cunningham replied that she had mentioned that the State department of social services held the compliance monitoring responsibility and that because of the State's budget tightening she was not surprised that the three positions were vacant.

Regarding religious preferences apparently shown by nursing homes under sectarian auspices, Ambers explained that Title VI of the Civil Rights Act of 1964 does not deal with discrimination based upon religion, and thus, religious based nursing homes are free to

⁵⁰See Marc Kaufman, "Nursing Home Bias Is Cited: Disputed Report: Race Is Factor," *Philadelphia Inquirer*, Oct. 13, 1991, p. B-1, and David B. Smith, "Nursing Home Stats: Bias Has Longevity," *Philadelphia Inquirer*, Oct. 25, 1991. Smith asserts that, "It's commonly assumed that the lack of financial resources rather than race explains racial discrepancies in nursing home use. However, it is race, not income, that is a far better predictor of access."

discriminate or give preferences. However, FRIA's report argued that "a lot of religious based nursing homes that do this are not truly religious based nursing homes, and they will accept white applicants from other religions but exclude minority people." As a consequence, FRIA alleged that such nursing homes "waived their exception as religious based organizations. They went away from the group that they purported to represent."

NEW YORK ASSOCIATION OF HOMES AND SERVICES FOR THE AGING

Carl S. Young, the president of the New York Association of Homes and Services for the Aging, described his agency as representing the not-for-profit and public providers for long-term care—about 400 institutions across the State, including 250 to 260 nursing homes. Of all these institutions, about 70 percent were religious based, and 20 percent of the public and of the rest are community based. Although their primary mission is to serve the elderly, long-term care is expanding, and some association providers serve AIDS or HIV-positive victims as well. Members have asked whether the changing population served by the association indicated that the association has changed its mission. After some deliberation, the association decided that it had not changed its mission, since "aging" is a process that is "all-encompassing, and we all begin that process at birth."

As to minority access, Young noted that the percentage of minority admissions "is about equal to the minority percent of the population statewide." According to a civil rights survey by the State department of health in 1990, just over 13 percent of the nursing home admissions was to minorities; however, in answer to a question from Advisory Committee member DeWitt Murray, Young said that the need for long-term care may be higher among minorities because of "lower overall health conditions," and that is "something you have to weigh when you take [the admission] figure into account."

Young then looked at the access issue from two perspectives. The first raised the question as to how minorities might themselves become long-term care providers.⁵¹ For minority based organizations, procurement of the necessary startup capital is a difficult problem, particularly in the urban areas of New York State where the cost of land is virtually prohibitive. His association has been working with a Baptist church in Buffalo that was in the process of buying a facility from a Jewish provider that is building a new facility and hoping to sell its present facility. The would-be providers have encountered "very severe problems, not the least of which is a State requirement for 10 percent equity just to get your service need in the door." He added that in 1987 a Baptist congregation in Brooklyn had its certificate of occupancy denied by the State because of the equity issue.

⁵¹See also deputy speaker Eve's comments, p. 7 above, and Simmons' recommendation in app. A.

Young's second "perspective" focused on management experience. He said that minorities have historically had only low levels of involvement in nursing homes except at the labor level. This has been particularly true in urban areas where there has been high employment of minorities as maids, orderlies, and so on.

As for access to services, besides the problems mentioned by others earlier, there is a question of bed availability, Young said. In some parts of the State, access is a problem for everyone. Another factor is bed availability at the level of care required. Method of payment is also a critical factor, and many of the current budget reduction proposals target medicaid funding which makes the medicaid beneficiary—who is disproportionately a minority—a less attractive patient. "Even though our members are not-for-profit, not-for-profit does not mean suicidal. You have to have a bottom line or you are not going to be able to carry on your charitable purpose," said Young. He added that "medicare is not really a player in New York State,"

Regarding minority admissions issues, Young indicated that he had served in his association for 2 years and had not heard of this discussed by association members as an issue or as "a fear that they are going to be required to take minorities, because I think the overwhelming majority of members—particularly in the urban areas—have populations in their facilities that are reflected in the general population." As for minority medicaid patients, he believed that they are admitted to facilities but, if denied admission, the location of the facility and the facility's case mix are far more important factors.

We are not talking about rich white people being accepted while the medicaid minority cannot get in. . . . If I am the provider and I have two medicaid patients come in, I want to know what their RUG [resource utilization group] category is. Are they Physical A, or are they complex? If they are complex, I want them. If they are Physical A, I would really rather not, if I can avoid it.⁵²

According to Young, a 1989 or 1990 study using 1988 data, the Lewin Study, concluded that:

70 percent of the facilities of the providers statewide are losing money on their medicaid residents. That figure is now even more difficult for public and not-for-profit [providers]. . . . Eighty-five percent of the not-for-profit [providers] lost money on their medicaid patients, and 96 percent of the public [providers] lost money on their medicaid patients.

⁵²See Horne, who writes, "some nursing homes may admit patients who have the ability to pay privately or whose care needs are relatively simple ahead of those who need heavy skilled care and/or public support for care." *The Nursing Home Handbook*, pp. 30-31.

If the medicaid patient becomes less attractive, the gap must be covered by private paying patients, more vigorous fund raising, or by providers branching off into other services such as home care or offering another level of service that might subsidize the original medicaid service, said Young.

Ambers commented that FRIA annually assists 4,000 people through the placement process. In New York City, virtually 80 percent are subsidized by medicaid, and virtually 100 percent of the nursing homes choose whom to admit and whom not to admit, and they ask for and receive all of the financial information they need to make the choice "they want to make in terms of their bank books." In terms of tax records, the nursing homes acquire everything they ask for, and, if an applicant will not produce such records, the nursing home refuses to process the application. Having heard Young mention the outside fund raising which some not-for-profit nursing homes do, Ambers observed that the white family of a medicaid applicant may acknowledge to a nursing home that, we "want our loved one to get in; we recognize our responsibilities to maintain your institution, too, you know, and your expansion program and building program."

That approach is not technically illegal, stated Young, and it may happen "when you have a wealthy middle class family whose relative has spent down [his or her] assets and is on medicaid. This gives them a chance to get their [relative] in over a minority [medicaid] applicant." Young said that another possible way to gain admission is for a person to come in as a private pay, having sheltered most of their assets. "They stay for 2 months as a private pay and go on to medicaid after a relatively short length of stay as a private pay." He added that, "Frankly, if you are really conniving about this as a family, you keep enough of the assets available so that they will have that private pay access and pay the private pay rate for 3 months, 6 months. Your assets are gone because you were able to properly utilize the law, and then you become a medicaid patient." But, he cautioned, this can be flirting with illegality.

On this point, a founder of the National Academy of Elder Law Attorneys wrote in a recent edition of the *Washington Post* that, "Laws in most States allow you to convert your assets to an annuity that pays you a monthly sum for the rest of your life. You must be careful that the payout period approximates the number of years you can be expected to live. Medicaid will disallow an annuity with a long payout that would benefit your heirs."⁵³

With regard to sectarian facilities making preferential admissions, Young explained that their reason for being is to make sure that the members of their religion are served, that is, that they have access to long-term care. In the mid-1980s, the State attorney general ruled that as long as religious preference was in fact a religious preference and not a disguise for discriminat-

⁵³"Seniors: Your Retirement Dollar," p. 18. See also *Elder Care*, pp. 7/2-15.

ing on the basis of race, the preference would not be unlawful. Young related the difficulties such preferences can sometimes create for association members. One facility was not only chartered to serve a specific religion but also to serve a particular sect within that religion, tying the administrator's hands, causing him serious difficulties. "He said to me, 'This practically means I am mandated to lose money if I can't raise \$2 million a year on outside fund-raising.'"

On the other hand, Ambers, FRIA's chief, suggested that:

we are spending too much time looking at the balance sheet of nursing homes. No nursing homes in New York City are going out of business. Everybody wants to be in the nursing home industry, and none of them is going into Chapter 11. . . . I don't know of one nursing home that has gone out of business or gone into Chapter 11 because of medicaid reimbursements.

In fact, asserted Ambers, after FRIA instigated an investigation by the special prosecutor's office in New York City, "two of the most prominent and well respected nursing homes in New York City, 2 or 3 years ago, pleaded guilty or nolo contendere to shaking down families of medicaid applicants" by asking for contributions against State law. Ambers made it clear that he was not implying that such abuse was widespread, but he repeated that the nursing homes in question were "two of the most prominent facilities in New York City."

Advisory Committee member Ciprich inquired if there are any studies or statistics on "case mix." Young responded that on the Thursday following the factfinding meeting there was to be a Hospital Review and Planning Council meeting "where the State is intent on recalibrating reimbursements because facilities have increased their case mix over the last 5 years, and the State is convinced that [facilities] did that, not by increasing the level of care to patients, but rather by manipulating the paperwork." His association, however, has documented the direct costs to patients and could fill a room with such data. Nishi explained that since Young indicated that case mix is a crucial factor, some data illustrating why it is a crucial factor would be welcome, though the data need not be massive.

Young urged the Advisory Committee to look beyond nursing homes. He said, "we cannot afford to continue dependent care," and, if other noninstitutional arrangements are not developed for the elderly, the problems already outlined may just become worse. Mentioning that his association also represents members providing senior citizens housing, Young said that, if such housing is increased and services delivered to, or in, that housing, nursing homes will be relieved of some pressure. A financial adviser offered a recent estimate in a national monthly,

indicating that an individual's savings in home health care could be significant.⁵⁴

Moreover, in the spring of 1990, a survey for the American Association of Retired Persons was released indicating that 86 percent of the respondents 55 and older preferred to stay in their own homes, up from 78 percent polled in 1986. "Their dominant preference is to stay in their homes, and not move, never move, and stay there forever," said an AARP housing specialist.⁵⁵ However, the same survey found that 35 percent had done no planning for their future, and an additional 18 percent had done only a little planning. One analyst speculated that many elders avoid thinking about future needs and alternatives until forced to do so by a calamity such as suffering a stroke or the death of a spouse. Meanwhile, developers were building "life-care facilities and congregate-care centers" which offer "some combination of meal preparation, health-care assistance, transportation services, long-term care insurance, and organized recreational activities."⁵⁶

More recently, an August 1992 *New York Times* article focused on daycare for the elderly. The director of a national demonstration program was cited as saying that "Adult daycare centers are the best kept secret in long-term care. . . . They are the No. 1 alternative to nursing home care."⁵⁷ Among the benefits listed are that such centers "offer impaired elderly people a wide array of health services and closely supervised recreational activities, as well as the opportunity to continue living at home." In addition, they also offer the care givers at home a respite from what could otherwise be a fulltime demand on their lives.⁵⁸ For those elderly requiring fewer services, an August 1992 monthly newsletter of the U.S. Census Bureau states that:

Recent demographic trends suggest that there is a growing need for 'board and care places'—living facilities that offer meals and care for people who have a dependency either through age or infirmity. . . . There are two types of facilities: 1) housing units sheltering one or more nonrelatives and 2) group quarters. Most provide housekeeping services and protective oversight (that is, someone who knows where the residents are and can provide help.) Many also provide other

⁵⁴In March 1992 one financial consultant estimated that home health care "can amount to approximately 50 percent or more of the annual cost of a nursing home." See Robert Fain, president, Fain Financial Services, "Myths of Long-Term Health Care," *USA Today: The Magazine of the American Scene*, March 1992, p. 22.

⁵⁵Kirstin Downey, "No Place Like Home for Elderly; Poll: Senior Centers Losing Their Appeal," *Washington Post*, Apr. 7, 1990, p. E-1.

⁵⁶Ibid.

⁵⁷"Day Care Offers a Better Life. . . ."

⁵⁸Ibid.

services as well—such as help with daily activities and transportation to medical appointments.⁵⁹

At the request of the U.S. Department of Health and Human Services, the Census Bureau undertook a project to discover if existing board and care facilities can be identified and located. The results “showed that the census does provide a usable sampling frame for a national study.”⁶⁰

For another alternative, Young recommended that the Committee consider seeking incentives for providers “as distinct from regulations to punish bad behavior. . . . I spent 16 years in government, in county government, and I know the impulse to regulate.” He said that insurance incentives would be useful. Some of the pressure on medicaid could be relieved if affordable long-term care insurance were available. “What is happening now is that medicaid is being used by the middle class and the well-to-do.” He pointed out that asset divestiture had recently been subjected to exposure, but now there are law firms whose sole practice is focused on enabling the middle class and well-to-do to divest their assets. He knew of a case where a nursing home resident died as a medicaid patient, yet the patient had \$8 million in his estate. Thus, the taxpayers got to subsidize a private inheritance of \$8 million.

A meaningful system of long-term care insurance with incentives to purchase the insurance would help, continued Young. The incentives might include tax credits for the purchaser so that sheltering assets would be unnecessary. He said that he was not suggesting that regulation has no place in such matters, but he believed that New York State is probably the most regulated State already. “New York State officials never met a regulation they didn’t like,” observed Young.

“Or didn’t enforce,” said Ambers. “Or enhanced, if they got the opportunity,” added Young.

LATINO GERONTOLOGICAL CENTER

Mario Tapia, president of the New York City based Latino Gerontological Center, has worked in the field of the aging for 15 years. He stated that his center addresses the situation faced by the Hispanic elderly, particularly in the northeastern United States, although it has a national board of advisers of diverse ethnic backgrounds who reside around the country from Puerto Rico to Los Angeles. Tapia announced that the center was collaborating with others to hold the first northeastern conference on the Hispanic elderly. Held in March 1992, the event

⁵⁹U.S. Census Bureau, “Census Bureau Survey Profiles ‘Board and Care’ Places,” *Census and You*, August 1992, p. 14.

⁶⁰*Ibid.*

included a luncheon address by the Chairperson of the neighboring Connecticut Advisory Committee who represented the Staff Director of the U.S. Commission on Civil Rights.⁶¹

During the factfinding meeting Tapia noted that there has been a dramatic change in New York State's demography, particularly in the city of New York which was home to 101,000 persons of Hispanic origin age 60 and over in 1980; by 1990, the number had increased to 163,000. Thus, during one decade the Hispanic elderly population of New York City grew by 61 percent, and he estimated that in 25 years, "statistical projections bring that number to well over half a million." According to Tapia, close to 90 percent of the Hispanic elderly are "Spanish monolingual," 46 percent live alone, and two out of three subsist near or below the poverty level.

Tapia asserted that discussions with older Latinos revealed that "they avoid going to a health care facility when sick, because they are convinced that they will get sicker."⁶² He also referred to a 1990 United Hospital Fund report which he said indicated that Hispanics constitute 4 percent of the nursing home population, even though the 1990 Census showed that Hispanics over 65 years are 11 percent of the total number of New York City's elderly.⁶³

As an indication of the problems they face in nursing homes, Tapia reported that a few years earlier he visited a centrally located home in the city where 500 of the 700 residents were Hispanics. "[T]here were no bilingual professionals on the staff nor were cultural provisions observed. This matter was brought to the attention of several administrators who later informed us that the menu would now include chili con carne." Pointing out that "we are entering the third decade of this country's ongoing discussion of the needs of the Hispanic elderly," Tapia judged that, "unfortunately, programs have been minimal." He also asserted that few resources from government, foundations, and private corporations have been allotted to Hispanics.

He submitted several recommendations including: developing community based research by Latino researchers to assess the needs of the Hispanic elderly; identifying and providing funding to Latino advocacy organizations; involving those organizations in the formulation of public policy aimed at benefitting both the present and future Latino elderly population;

⁶¹Representing Staff Director Wilfredo J. Gonzalez of the U.S. Commission on Civil Rights, Dr. Ivor J. Echols, Chairperson of the Connecticut Advisory Committee, gave the main luncheon address on Mar. 21, 1992, at the conference of the Latino Gerontological Center held in Hartford, Connecticut. See app. C.

⁶²According to a nationally cited study, "The nation's nearly 1 million Hispanic elderly have poorer health, less access to medical care, are more likely to live in poverty, and are less educated than their non-Hispanic counterparts." See Felix Perez, "Elderly Endure Poor Health, Poverty," *Hispanic Link Weekly Report* (Washington, D.C.), Sept. 18, 1989, p. 1.

⁶³See census statistics for New York State residents who were age 65 and over in 1990 on p. 2 above.

designing and promoting effective models of service delivery and long-term care for the Latino elderly; providing technical assistance to community groups in terms of organizing and grantsmanship for program development; and training gerontological specialists who will work with the Latino elderly. Commenting that social change requires social courage and special people to implement change, Tapia thanked the Advisory Committee for holding the factfinding meeting. He then circulated copies of an article he wrote as published in *El Diario* the previous Friday, which dealt with the Advisory Committee's factfinding meeting.

Advisory Committee member Juan Padilla said that, as a Hispanic, he confirmed that most Hispanics prefer to have their elderly remain in the home with their families, but sometimes the arrangement causes problems that discourages everyone. He asked how it might be possible to balance the cultural desire of keeping the elderly at home with the reality of placing them in a nursing home where needed long-term care is available, though sometimes not good.

Young responded that the question goes back to his earlier recommendation that other program approaches be developed such as the assisted living program or the expansion of home care attendant services. Tapia commented that one aspect of the problem has to do with the economics of housing in New York City where so many living quarters are studio size or other small apartments, making it difficult for a family to take in grandparents. He also said that resources are central to the problem and that many organizations try to keep minority groups away from the resources.

Ambers remarked that FRIA has been surprised to find that:

the Catholic-sponsored nursing homes had very few Hispanics and virtually no West Indian blacks who are also members of the Catholic faith. This was a case where the so-called religious based nursing homes might have been religious based—but for the white religious and not for the black and Hispanic religious.

NEW YORK CITY COUNCIL PRESIDENT'S OFFICE

Sara Vidal, special assistant to New York City Council president Andrew Stein, expressed regret that a prior commitment prevented the city council president from being able to participate. She remarked that the council president has long been involved in issues affecting the elderly, including the time when there was a nursing home crisis in the city. For this reason, many elderly individuals come to his office for assistance. Less than 2 months earlier, the council president convened a public hearing on problems facing the Hispanic elderly and "speaker after speaker . . . illustrated the horrendous living conditions of the older Hispanic New Yorkers . . . [and the] major barriers affecting the Hispanic elderly that revolve around language,

cultural awareness and lack of services.”

She reported that despite many governmental policies and regulations requiring bilingual workers in many agencies and not-for-profit organizations, the Hispanic elderly remain unable to access services because of the lack, or insufficient number, of bilingual workers, according to witnesses. The traditional word-of-mouth method of gaining information for Hispanics has left the Hispanic elderly untouched by some of the conventional outreach methods. Their lack of information was documented in a 1989 Commonwealth Fund study⁶⁴ showing that only 44 percent of Hispanics eligible for SSI are enrolled, and that more than a quarter of those potentially eligible said they had never heard of SSI. Again, though most Hispanic elderly are also eligible for some form of publicly assisted housing, they are uninformed about what is available.

With insufficient time to elaborate upon the council president’s hearing, Vidal submitted the prepared statement of the city council president and a transcript of his hearing.⁶⁵

ASOCIACION NACIONAL PRO PERSONAS MAYORES

The Asociación Nacional Pro Personas Mayores is headquartered in Los Angeles, but an east coast representative was invited to participate in the factfinding meeting. Although the arrangements ultimately could not be worked out, Carmela G. Lacayo, the president and chief executive officer of the Asociación, submitted a written statement for the record.

Among the points made by Lacayo was one indicating that, “U.S. Hispanics tend to age faster than older Anglos, since many [Hispanics] have worked all their lives in physically demanding, low-paying jobs. It is more accurate to define old age for Hispanics at 55 years and over.” She further observed that, “the Hispanic elderly are among the most in need of adequate long-term care—both formal (government-assisted) and informal (provided by family, friends, or other care-givers.) Yet older Hispanics also rank among the lowest users of long-term care.”⁶⁶

Noting that the Hispanic community cannot be expected to have its elderly cared for by a member of the family at the same rate that family members do so today, like Young, Lacayo

⁶⁴Jane Andrews, assistant director, The Commonwealth Fund, *Poverty and Poor Health Among Elderly Hispanic Americans*, The Commonwealth Fund Commission on Elderly People Living Alone, September 1989.

⁶⁵See app. D, for council president Stein’s prepared statement.

⁶⁶Carmela G. Lacayo, president and chief executive officer, Asociación Nacional Pro Personas Mayores, “Testimony on the Hispanic Elderly and Their Need for Long Term Care,” Oct. 29, 1990. See app. E.

called for a system that would include inhome and community-based care as part of a national health insurance program. This past spring a May 5, 1992, *Washington Post* article reported that:

A third of all Hispanics were uninsured in 1990, while 19.7 percent of blacks and 12.9 percent of whites had no [health] insurance, according to the study prepared by the National Council of La Raza and the Labor Council for Latin American Advancement. . . . Hispanic people also had difficulty gaining access to Medicaid, the public health insurance program for the poor, because many live in States with the most stringent eligibility criteria.⁶⁷

⁶⁷"Hispanic Residents Often Lack Health Coverage," *New York Times*, May 5, 1992, and see also, "Study: Hispanics Low on Health Insurance," *Washington Post*, May 5, 1992.

S U M M A R Y

Almost 30 years after the New York State Advisory Committee issued a report finding racial discrimination in hospitals serving the Buffalo area, 18 knowledgeable panelists, speaking from diverse points of view, informed the Advisory Committee of the status of the minority elderly in terms of their health needs and the limited access which the minority elderly experience when seeking long-term care in nursing homes. The panelists included the deputy speaker of the New York State Assembly who also chairs the Assembly's legislative committee on the minority elderly, several State and county officials, the Acting Regional Manager of the Office for Civil Rights of the U.S. Department of Health and Human Services, top executives of associations of nursing homes, university scholars, advocates, and others.

Beginning with the Assembly's deputy speaker, all agreed that the minority elderly are among the most vulnerable members of society. A physician ministering to minorities and the NAACP/Buffalo branch president addressed the failings of the U.S. health delivery system, which was described as drastically disadvantaging the poor in general and blacks in particular. Several panelists, including two university researchers, reported that blacks have the shortest lifespan and concomitantly a dire need for services ranging from physician care to help in shopping and that these needs are not met to the same degree that the needs of their white counterparts are met. Two others spoke of the special plight of Hispanics. Some public officials, a nursing home association head, and a consumer advocate—all of whom are active every workday in some aspect of long-term care in nursing homes—agreed that the elderly who must rely on medicaid upon admission are less likely to gain admittance to nursing homes than those able to pay or "spend down" their assets upon acceptance.

Whether or not discrimination on the basis of race or religion was the key factor remained an open question for some who felt that the evidence available did not necessarily warrant such a conclusion. For one thing, all agreed that the system for collecting data—on who applies as well as on who is or is not admitted—is inadequate, and does not yield sufficient data to determine if racial bias is a major factor. For another thing, a State official mentioned that minorities make up more than three-fourths of those gaining admissions in New York City but less in upstate New York. Several explained that all nursing homes are entitled to choose a "private pay," that is, an applicant who can pay upon admittance, over a medicaid eligible applicant who cannot, and minorities tend more to be in the latter category. A few pointed out that certain nursing homes may legally accept members belonging to the same religion or fraternal association in preference to others, and the complexities of the hospital discharge planning process were also mentioned. Heads of a Federal civil rights enforcement unit and a State civil rights monitoring unit reported that only a handful of complaints had been filed in years.

On the other hand, the director of an advocacy agency charged that some sectarian

nursing homes fail to admit applicants who are of the same religion but of a different race. Several panelists voiced suspicions about some reasons that nursing homes may proffer as rationalizations as to why a medicaid eligible minority applicant cannot be admitted. At least two panelists candidly described how white applicants with some assets may arrange their finances to be able to gain admittance and not long thereafter also resort to medicaid for support. A few discussed what they called the myth that minority families take care of their own elders. More than one believed that racial discrimination was at work against minorities, especially blacks and Hispanics, and the assembly's deputy speaker asserted that a State publication had shown that minorities are discriminated against in nursing home admissions in the State.

Two court cases were also alluded to, one against the State of Tennessee, the other against the State of Pennsylvania. A U.S. district court has agreed with the black plaintiffs in Tennessee that dependency on medicaid has a disparate and adverse impact on black applicants; the case in Pennsylvania has not yet been decided. In view of the Tennessee precedent, what was learned during the two factfinding meetings held by the Advisory Committee on each side of New York State, and information gathered through additional research, the Committee generally finds it reasonable to suspect that in New York State, discrimination on the basis of race plays a role in the rejection of at least some minorities by the nursing homes to which they apply for long-term care.

FINDINGS AND RECOMMENDATIONS

Based on the foregoing, the New York State Advisory Committee offers the following findings and recommendations.

1. Finding:

The system for collecting nursing home admissions data in New York State yields information by race/ethnicity on who has been accepted for admission to a nursing home but *not* on who was denied admission.

Recommendation:

The data collection systems in New York State and elsewhere should be reviewed by the U.S. Department of Health and Human Services and modified to include data by race/ethnicity on who applied but was denied admission.

2. Finding:

With nursing homes in New York State now less free to limit the number of beds that can be used by medicaid-eligible applicants, the disparate and adverse impact previously affecting medicaid-dependent minorities has presumably lessened.

Recommendation:

The State policy now regulating nursing homes in terms of their limiting medicaid-eligible beds should be monitored by the New York State Health Department and the U.S. Department of Health and Human Services, with reports published on whether minority applicants continue to be disproportionately affected by their dependency on medicaid.

3. Finding:

There continues to be a limit on the number of nursing homes built in New York State, and the resultant shortage of nursing homes in the State also has some bearing on the

shortage of nursing home beds available to the minority elderly.

Recommendation:

The U.S. Department of Health and Human Services should review the issue of limitations on the number of nursing homes allowed by States—including any limitations inherent in the criteria and process for approving applications to create nursing homes—and should determine whether such limitations exert a disparate adverse impact on the minority elderly.

4. **Finding:**

The number of complaints of discrimination received by the New York State Department of Health and by the U.S. Department of Health and Human Services has been markedly low.

Recommendation:

The New York State Department of Health and the U.S. Department of Health and Human Services should become more proactive by initiating a study of why so few complaints are made and by launching other studies. These other studies should include a study of the discharge planning process at a sampling of hospitals to measure to what extent the hospital discharge planning process may produce discriminatory effects.

5. **Finding:**

The meager number of complaints received by the New York State Department of Health and the U.S. Department of Health and Human Services appears to be due at least in part to confusion or ignorance among minority applicants about what they may legitimately expect from nursing homes.

Recommendation:

Improved outreach and educational measures must be taken by the New York State

Department of Health and the U.S. Department of Health and Human Services to inform hospital discharge planners, other health care providers, and minority elders and their families about ways of ensuring that minority elders enjoy equal opportunities to long-term care.

6. **Finding:**

Some minority elders, especially from language-minority communities, are inadequately or inappropriately cared for once admitted into a nursing home.

Recommendation:

Enforcement and monitoring agencies at the Federal, State, and local levels must acquire the capacity to review the cultural and/or linguistic needs of minority elders and must utilize that capacity when their compliance reviews or studies are carried out.

7. **Finding:**

Few nursing homes in New York State and elsewhere are minority-owned and/or minority-operated.

Recommendation:

To increase the number of nursing homes that would be more sensitive to the needs of minorities, the New York State Department of Health and the U.S. Department of Health and Human Services should explore, with the small business development agencies of their respective levels of government, how minorities might be helped to enter the nursing home field.

8. **Finding:**

Even were the supply of nursing homes not limited, nursing homes do not represent the

ideal option for every elderly person in need of long-term health care, especially for the minority elderly.

Recommendation:

Recognizing cultural considerations, the U.S. Department of Health and Human Services, and the New York State Department of Health should explore and/or increasingly support alternatives to nursing homes when the alternatives are consistent with the cultural characteristics and background of the minority elders to be served. Such alternatives might include so-called life care facilities, congregate care centers, and adult day care centers.

The National Caucus and Center on Black Aged, Inc.



1424 K Street, N.W., Suite 500, Washington, D.C. 20005 / 202 637 8400 FAX # 202 347 0895

Hobart C. Jackson
Founder NCBA 1970
1976-1978

Dr. Aaron E. Henry
Co-Chairman

Gomarr L. Black, Jr.
Co-Chairman

Samuel J. Simmons
President

July 23, 1992

Mr. Tino Calabia,
U.S. Commission on Civil Rights
Eastern Regional Division
1121 Vermont Avenue, N.W., Rm. 710
Washington, D.C. 20425

APPENDIX A

Dear Mr. Calabia:

We appreciate the opportunity to review the draft of the U.S. Commission on Civil Rights New York State Advisory Committee report on Minority Access to Health Care and Nursing Homes. The treatment of minorities by the long term care industry and system has long been a priority issue for the National Caucus and Center on Black Aged. I enclose for the Committee's review three reports issued by NCBA since 1985 which deal with long term care particularly as it relates to the minority elderly. They are:

REPORT AND RECOMMENDATIONS -- Long Term Care Committee, National Caucus and Center on Black Aged, Inc., 1985;

STATEMENT ON LONG-TERM CARE -- The National Caucus and Center on Black Aged, Inc., October 1989;

STATEMENT BY NATIONAL CAUCUS AND CENTER ON BLACK AGED, INC. ON ELIMINATING DISCRIMINATORY PRACTICES IN NURSING HOMES, September 1990.

With respect to the specific issues addressed by the Committee, we offer the following:

A far greater effort must be made by the nursing home industry and regulatory system to recruit, train and retain minority individuals as managers of nursing home facilities and nursing home companies. Of the thousands of nursing homes nationwide, less than 200 (recent statistics are not available) are headed by minority administrators. By having minority individuals at the helm of the facilities and companies, some of the overt and incidental discriminatory practices should be alleviated. Additionally, those minorities who have gained admission to nursing homes would find themselves in facilities which are more sensitive to their culture making their residencies more comfortable and less traumatic. There exists in the minority community a mistrust of nursing homes based on historic and present day discrimination. The presence of minority managers would help to alleviate that mistrust and reduce the trauma and stigma associated with nursing home placement.

Incentives must be found to increase the numbers of minority-owned long term care facilities. These facilities traditionally employ the greatest numbers of minority managers and admit the greatest numbers of minority residents. Since minority access has been shown to be a problem, one solution should be to assist minorities with owning their own facilities especially those which are based in minority communities. Incentives such as assistance with start up capital, tax breaks, increased Medicaid payment levels for homes which serve a high percentage of minority patients should be utilized to create more ownership opportunities for minorities wishing to own facilities.


NCBA
Page two

One issue which was mentioned during the hearing was hospital discharge planning. Monitoring and training of discharge personnel must take place to prevent minority patients from being steered away from quality nursing facilities. The Advisory Committee may wish to study the recommendations of discharge planners relative to the race of the patient to ascertain their impact on nursing home admissions.

NCBA recognizes the many regulatory and financial burdens placed on nursing home operators. Many may truly want to serve low income and minority residents. However, our current health care system is inadequate and inequitable. It allows sophisticated individuals, who are mainly upper income, to shelter or transfer assets and to use the Medicaid system as their own national health insurance program. The low income are unable to gain access to long term care in many instances because of their economic undesirability while the middle income can be quickly impoverished when they or a family member need long term care. NCBA believes that the ultimate solution is a reform of the health care system to provide a national health insurance program which includes long term care. National health insurance would assure that all citizens would have at least the economic resources to gain access to long term care facilities. Until this occurs however, states and the federal government, advocacy organizations and others must continue to push the current system to admit many more minorities than are now being admitted.

We commend the New York State Advisory Committee of the U.S. Commission on Civil Rights for holding hearings and issuing this report on minority access to nursing homes. We hope that an improvement in the minority admission rate will ultimately result.

Yours truly,



Samuel J. Simmons
President and Chief Executive Officer

enclosures



STATE OF NEW YORK
DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.
Commissioner

OFFICE OF HEALTH
SYSTEMS MANAGEMENT
Raymond Sweeney
Director
Brian Hendricks
Executive Deputy Director

July 27, 1992

Mr. Tino Calabia
New York State Advisory Committee
United States Commission on Civil Rights
Eastern Regional Division
1121 Vermont Avenue, N.W. Rm. 710
Washington, D.C. 20425

APPENDIX B

Dear Mr. Calabia:

Your letter to Commissioner Chassin was referred to the Bureau of Health Facility Coordination for reply.

As you requested we "faxed" you a copy of our so called Medicaid access regulations, 10 NYCRR 670.3, and are attaching a copy for your files.

Thank you for sharing the report with us and with Mr. William B. Carmello. If we can help you further or you have any questions, please let me know.

Sincerely,

Mindaugas Jatulis
Assistant Director
Bureau of Health Facility Coordination

Attachment

cc: Mr. Berger
Mr. Carmello

Effective Date: September 18, 1989

SECTION 670.3

Residential health care facilities. (a) Notwithstanding the provisions of subdivisions (a), (b) and (c) of section 670.1 of this Part, the factors, methodology and procedures to be used by the Public Health Council for determining the public need for residential health care facility beds shall include, but not be limited to, the substantive criteria, methodology and procedures set forth in section 709.3 of this Chapter and the provisions of subdivision (c) of this section.

(b) Any application for establishment wherein a determination of public need is made pursuant to this section, shall be subject to the provisions of subdivision (d) of section 670.1 of this Part.

(c)(1) In determining the need for residential health care facilities, beds and services, consideration shall be given to the needs of persons who receive or are eligible to receive medical assistance benefits at the time of admission to a facility pursuant to Title XIX of the federal Social Security Act and Title 11 of Article 5 of the State Social Services Law, hereafter referred to as Medicaid patients, and the extent to which the applicant serves or proposes to serve such persons, as reflected by factors including, but not necessarily limited to, the applicant's admissions policies and practices. An application by an applicant that is or will be a provider that participates in the medical assistance (Medicaid) program shall not be approved unless the applicant agrees to comply with the requirements of this subdivision. An applicant that, at the time of consideration of its application by the Public Health Council, proposes not to participate in the Medicaid program may be approved, provided all other review criteria have been met, upon the condition that if, in the future, it does participate in the Medicaid program, it would comply fully with the requirements of this subdivision.

(2) To ensure that the needs of Medicaid patients in an applicant's service area are met and that such patients have adequate access to appropriate residential health care facilities, beds and services, applicants shall be required to accept and admit at least a reasonable percentage of Medicaid patients as determined pursuant to this subdivision. Such reasonable percentage of Medicaid patient admissions, also referred to herein as the Medicaid patient admissions standard, shall be equal to 75 percent of the annual percentage of all residential health care facility admissions, in the long term care planning area in which the applicant facility is located, that are Medicaid patients. The calculation of such planning area percentage shall not include admissions to residential health care facilities that have an average length of stay of 30 days or less. If there are four or fewer residential health care facilities in a planning area, the applicable

Medicaid patient admissions standard for such planning area shall be equal to 75 percent of the planning area annual percentage of all residential health care facility admissions that are Medicaid patients or 75 percent of the annual percentage of all residential health care facility admissions, in the health systems agency area in which the facility is located, that are Medicaid patients, whichever is less. In calculating such percentages, the department will use the most current admissions data which have been received and analyzed by the department. An applicant will be required to make appropriate adjustments in its admissions policies and practices so that the proportion of its own annual Medicaid patient admissions is at least equal to 75 percent of the planning area percentage or health systems agency area percentage, whichever is applicable.

(3) The proportion of an applicant's admissions that must be Medicaid patients, as calculated under paragraph (2) of this subdivision, may be increased or decreased based on the following factors:

- (i) the number of individuals within the planning area currently awaiting placement to a residential health care facility and the proportion of total individuals awaiting such placement that are Medicaid patients, provided that patients awaiting placement include, but need not be limited to, alternate level of care patients in general hospitals;
- (ii) the proportion of the facility's total patient days that are Medicaid patient days and the length of time that the facility's patients who are admitted as private paying patients remain such before becoming Medicaid eligible;
- (iii) the proportion of the facility's admissions who are Medicare patients or patients whose services are paid for under provisions of the federal Veterans' Benefit Law;
- (iv) the facility's patient case mix based on the intensity of care required by the facility's patients or the extent to which the facility provides services to patients with unique or specialized needs;
- (v) the financial impact on the facility due to an increase in Medicaid patient admissions.

(4)(i) An applicant shall submit a written plan, subject to the approval of the department, for reaching the Medicaid patient admissions standard required by this subdivision. The plan shall provide for reaching the standard within no longer than a two year period and the facility shall give preference, as necessary, to Medicaid patients in order to reach

the admissions standard within the prescribed time period.

(ii) Once the Medicaid patient admissions standard is reached, the facility shall not reduce its proportion of Medicaid patient admissions so as to go below the standard unless and until the applicant, in writing, requests the approval of the department to adjust the standard and the department's written approval is obtained. In reviewing requests to adjust a facility's Medicaid patient admissions standard, the department shall consider factors which may include, but need not be limited to, those factors set forth in paragraphs (2) and (3) of this subdivision.

(iii) After a facility's initial Medicaid patient admissions standard has been reached, the department may increase such facility's Medicaid patient admissions standard, based on the criteria set forth in this subdivision, if the percentage of Medicaid patients admitted by residential health care facilities in the facility's planning area or health systems agency area, as appropriate, increases due to factors other than an increase in Medicaid patient admissions by the applicant.

(5)(i) Subject to the provisions of subparagraph (ii) of this paragraph, after the phase-in period provided for in paragraph (4) of this subdivision, a facility shall be prohibited from failing, refusing or neglecting to accept or admit a Medicaid patient for whom it is otherwise able to provide care, regardless of whether the level of reimbursement received for such patient is less than the rate the facility charges private pay patients, unless the facility has reached and is maintaining compliance with the Medicaid patient admissions standard imposed by this subdivision. Compliance with the requirements of this subdivision shall be determined on the basis of a facility's total annual admissions, so that a facility may exercise its discretion in determining when during a year it will admit a sufficient number of Medicaid patients to maintain its Medicaid patient admissions standard.

(ii) A facility may be exempt from the requirement of admitting a Medicaid patient in order to meet or maintain its Medicaid patient admissions standard if it can demonstrate in writing to the satisfaction of the commissioner that the Medicaid patient was denied admission solely in order to admit another patient who had a greater need of residential health care facility services, as determined by the intensity of care anticipated to be required by such patient, and that there was only one bed available in the facility at the time of the admission decision to accommodate a new admission. Facilities shall not be required to obtain prior department approval in order to accept a non-Medicaid patient in place of a Medicaid patient pursuant to this subparagraph, but shall maintain sufficient documentation

including, but not necessarily limited to, a copy of the Patient Review Instrument for the patient admitted and the Medicaid patient denied admission in order to justify the admission decision. Copies of such documentation shall be provided to the department upon request

Volume: 10D

Remarks of Ivor J. Echols, DSW
Chairperson
Connecticut Advisory Committee
to the
U.S. Commission on Civil Rights

APPENDIX C

March 21, 1992 Luncheon Address
Northeastern Conference on Hispanic Elderly
Hartford, Connecticut

Thank you for your kind introduction. I am delighted to be here today, though--like you--I am disappointed that the Commission's Staff Director, Wilfredo J. Gonzalez, has been unable to join you, as he had originally planned, and he sends his regrets.

Let me start by saying that included in the jurisdiction of the Commission is discrimination on the basis of age. In fact, Mr. Gonzalez himself is soon to have an article appear in **OCR Report**, a newsletter of the U.S. Department of Health and Human Services, on the question of what access minorities have to nursing home care.

I should point out that in his article Mr. Gonzalez cites information recently provided by President Mario Tapia of the Latino Gerontological Center, a cosponsor of today's Conference. Mr. Tapia had made a presentation to the Commission's New York State Advisory Committee this past December, describing some of the problems encountered by Puerto Ricans and other Latinos in nursing homes in New York City. For example, a lack of effort to meet specific needs of older Latinos in terms of their linguistic and cultural background was cited by Mr. Tapia and mentioned in Mr. Gonzalez' article.

Mr. Gonzalez also referred to Linton and Carney v. Tennessee Commissioner of Health and Environment, the 1990 case in which a Federal District Court decided that the plan of the State of Tennessee for the certification of beds for Medicaid recipients had a disparate impact upon the admission and retention of minorities in nursing homes. In short, Medicaid discrimination was viewed as tantamount to racial discrimination, when the number of nursing home beds made available to Medicaid recipients is limited.

Last summer, a complaint was filed in the Federal District Court in Philadelphia alleging that three State agencies had failed to halt a widespread practice of discrimination affecting poor blacks seeking access to nursing homes in Pennsylvania. I am not a lawyer, and so, for more information on the reasoning underlying the Tennessee and Pennsylvania cases, let me refer you to organizations such as the Washington, D.C.-based National Citizens' Coalition for Nursing Home Reform. Towards the end of this year, the report of the New York State Advisory Committee which held the forum addressed by Mr. Tapia last December should be available; it, too, will contain information on these cases.

The New York report will also highlight the various needs described not only by Mr. Tapia but by New York City Council President Andrew Stein as well. In his remarks to the Advisory Committee, the City Council President catalogued the problems which plague older Hispanics in New York and which have worsened with cutbacks in Federal funding.

Let me also mention two already published Advisory Committee reports of possible interest: the Vermont Advisory Committee's **Ageism Affecting the Hiring and Employment of Older Workers** and the Delaware Advisory Committee's **Nutrition Services for Minority Elderly**.

At a 1989 forum, the Vermont Advisory Committee heard representatives of three State

agencies including the State Attorney General's Office, heads of two voluntary agencies, a University of Vermont business school professor who had surveyed employer attitudes, an attorney who had represented older job-seekers as well as employers, and a spokesperson for the American Association of Retired Persons. Six older workers also described their qualifications and job-seeking experiences.

The frustration, even anger, at being refused a job due to one's age was seen in detail--from the viewpoint of older workers and from the viewpoint of job counselors, an attorney, and a researcher. Yet some surprises were also learned during the Vermont project. As only one example, the Vermont report points out that during the forum, various statements were made suggesting that Federal law or regulations prohibit an employer from inquiring about a job-seeker's age. But the day after the forum, the area director of the U.S. Equal Employment Opportunity Commission's Boston office explained that there are no Federal prohibitions against inquiring about a job-seeker's age.

Of course, such information learned during a project may not make the older worker's job-search any easier. But at least the older worker and his or her advocates become better informed as to what the full reality of job-searching is.

In Delaware, the Advisory Committee held a forum in 1989 and learned how the limitations in census data can affect a review of whether older Latinos are receiving their fair share of Federally funded nutrition services. During that forum, an OCR representative reported that services in the State generally appeared to be in compliance; but "[OCR was] not able to establish that meaningfully in terms of the Hispanic community. . . ." This related to the weaknesses in how the 1980 census data were formatted for specific locations.

During the same forum, the head of an agency serving Latinos noted that Hispanics had been undercounted in the 1980 Census and also that Hispanic communities had high rates of growth. She outlined how she arrived at an updated estimate of older Latinos that suggested there were over 680 Latinos over the age of 60 in the State in 1989, many more than just the 402 counted in the 1980 Census.

If it could have been scientifically demonstrated that the estimates by one person, such as the forum speaker, were reasonably accurate, the question of whether older Latinos were receiving their fair share of some Federally funded programs might have been answered. Of course, scientific proof is difficult to develop in a setting such as an Advisory Committee forum. But a lesson to be drawn from the discussion was that whether older Latinos were being equitably treated remained a question and that everyone must pay heed to the development of statistical data on Latino communities.

At any rate, should you be interested in receiving the Vermont report on employment, the Delaware report on nutrition services, or the upcoming New York State report on nursing homes, I shall be happy to have staff mail you copies. For anyone who is a resident of Connecticut, let me note that the Connecticut Advisory Committee has to date not focussed on ageism or problems affecting older Americans. Next month, on April 27th, we are holding a forum on bias-related tensions experienced on college campuses. After that project is completed, we will choose a new civil rights issue to investigate. If you have any recommendations, you are welcome to attend our Committee meetings to make them known to us.

For now, on behalf of Mr. Gonzalez and the Commission, let me express our gratitude for the invitation to join you today to tell you about what the Commission and its State Advisory Committees do and have done, especially in terms of your interest in the civil rights of older Americans. Thank you.

APPENDIX D



THE CITY OF NEW YORK
THE PRESIDENT OF THE COUNCIL
CITY HALL
NEW YORK, N. Y. 10007

ANDREW STEIN
PRESIDENT

(212) 788-3200

TESTIMONY BEFORE NEW YORK STATE ADVISORY COMMITTEE
TO U.S. COMMISSION ON CIVIL RIGHTS
"MINORITY ELDERLY AND THEIR ACCESS TO NURSING HOMES"
HISPANIC ELDERLY

PRESENTED BY: Council President Andrew Stein

December 4, 1991

Madame Chair, Mr. Calabia, Advisory Committee Members and Guests. Thank you for the opportunity to present testimony before the New York Advisory Committee to the U.S. Commission on Civil Rights and this distinguished panel.

GOOD MORNING! As you may already know, I recently held a public hearing on problems facing Hispanic elderly. In New York City the number of Hispanic elderly has increased dramatically. The 1990 Census reported more than 150,000 persons of Hispanic origin 60 years and over in New York City. This figure represents approximately 12 percent of the total elderly population. Actually, the Hispanic elderly is the fastest growing segment of the elderly population in the City of New York and is expected to quadruple by the year 2000.

Speaker after speaker at the hearing illustrated the horrendous living conditions of older Hispanic New Yorkers. They confirmed that the major barriers affecting the Hispanic elderly revolve around: language, cultural awareness and lack of access to services and information.

Despite the many governmental policies and regulations requiring bilingual workers in many agencies and not-for-profit organizations, older Hispanics are still unable to access services because of the lack of, or insufficient number of, bilingual workers. Older Hispanics are usually Spanish monolingual and poorly educated and, therefore, illiterate in both English and Spanish. Many are intimidated by the forms and paper work that are required to be completed by agencies before they provide services to the elderly. Further, many speakers at the hearing identified that lack of information is in itself a barrier that prevents older Hispanics from taking advantage of services for which they qualify. Traditionally, elderly Hispanics rely on information delivered to them by word of mouth. Therefore, the conventional outreach methods are not successful with this constituency.

Lack of access to information prevents Hispanics from using available entitlements. The 1989 Commonwealth Fund Study, Poverty and Poor Health Among Hispanic Americans, states that 44% of the Hispanics who are eligible for Supplemental Security Income (SSI) are enrolled and that more than a quarter of those potentially eligible said they had never heard of SSI before. SSI benefits are crucial for the Hispanic elderly because they earn or have earned low incomes and most retired from low paying jobs with little or no pension and health insurance benefits.

At the hearing, witnesses stated that Hispanic elderly live in substandard housing and are concentrated in poverty stricken areas of New York City. These areas are replete with dilapidated buildings and buildings that violate the housing code. Added to this stressful situation is the fact that many elderly tend to live with family members. A study done by the Partnership for the Homeless in 1989, estimated that between 45,600 and 52,500

Hispanic families live in doubled and tripled-up situations in New York City.

Housing in New York City has become even more scarce and substandard as federal funding has decreased. Hispanic elderly are uninformed about what is available in housing for them. Although most Hispanic elderly are eligible for some type of housing subsidy; i.e., Section 8 Housing Assistance Programs, Section 202 Senior Citizen Housing or Senior Citizen Rent Increase Exemption (SCRIE), the complex rules and regulations governing these programs, coupled with a lack of publicity, prevent the Hispanic elderly who might prefer living alone from taking advantage of them.

To insure better quality of life, information and language problems of the Hispanic elderly must be addressed. I will continue to examine the issues and recommendations that surfaced during the course of testimony presented at the Public Hearing on the Hispanic Elderly. A copy of said testimony is being provided to the New York Advisory Committee to the U.S. Commission on Civil Rights for the record. Thank you for this opportunity.

CARMELA G. LACAYO
President/CEO
JUDGE NELSON A. DIAZ
Chairman of the Board



ASOCIACION NACIONAL PRO PERSONAS MAYORES

APPENDIX E

TESTIMONY ON

THE HISPANIC ELDERLY AND THEIR NEED FOR LONG TERM
CARE

SUBMITTED BY

CARMELA G. LACAYO
PRESIDENT/CEO
ASOCIACION NACIONAL PRO PERSONAS MAYORES
LOS ANGELES, CALIFORNIA

BEFORE THE

NEW YORK STATE ADVISORY COMMITTEE
U.S. COMMISSION ON CIVIL RIGHTS
BUFFALO, NEW YORK HEARING

OCTOBER 29, 1990

REGIONAL CENTERS:
Los Angeles, CA • San Diego, CA • Washington, DC • Miami, FL • Tampa, FL • Chicago, IL •
New Orleans, LA • Detroit, MI • Philadelphia, PA • Kansas City, KS • San Antonio, TX • Laredo, TX •

REGIONAL CENTERS:

I. INTRODUCTION

Dr. Ol, Assemblyman Eve, and Committee members, the National Association for Hispanic Elderly thanks you very much for this opportunity to testify about the Hispanic elderly and their need for long term care. As the first national organization founded to serve older Hispanics, we commend the New York State Advisory Committee for holding this timely and important hearing.

The Hispanic elderly are among those most in need of adequate long term care – both formal (government-assisted) and informal (provided by family, friends or other caregivers). Yet older Hispanics also rank among the lowest users of long term care. Our testimony focuses on why older Hispanics' need for long term care is so great, why this group underuses such care, and what can be done about it.

II. DEMOGRAPHIC OVERVIEW

Hispanic older persons are one of the fastest-growing but most underserved segments of our population. At the outset it is important to define "Hispanic elderly." Most government offices define old age as 65 years and over. But U.S. Hispanics tend to age faster than older Anglos, because many have worked all their lives in physically demanding, low-paying jobs. It is more accurate to define old age for Hispanics at 55 years and over. This means that official statistics on older Hispanics underestimate the size and needs of this group.

About two million Hispanics aged 55+ lived in this country in 1987. The Census Bureau estimates that the Hispanic group aged 65+ will grow by 217 percent between 1987 and 2015 – to a total of over three million people – compared to an increase of 50 percent among all U.S. elderly. This booming population shares the Spanish language and, to some extent, a history. But older Hispanics are a heterogeneous group that varies regionally and culturally.

In 1988 aged Hispanics were more than twice as likely to be poor as older Anglos: 22.4 percent versus 10.0 percent (U.S. Department of Commerce, 1988). Social Security and Supplemental Security Income represent almost three out of every five dollars (57.3 percent of total support) received by the Hispanic elderly. Their unemployment rate (5.2 percent) was almost doubled that of the dominant population (2.4 percent) in 1987 (U.S. Department of Labor). This is due

in part to educational disadvantage. Nearly 31 percent of all Hispanic men 65 years or older and 31.5 percent of older Hispanic women were functionally illiterate in 1987: They had less than five years of schooling. This rate is six to seven times as great as for older Anglos (U.S. Department of Commerce, March 1987).

Older Hispanics are in poorer health than their Anglos counterparts. One measure of this fact is the incidence of "disability days" they experience. In 1986 31.5 percent of older Hispanics were bedridden for 1 to 30 days, compared to 21.9 percent of elderly Anglos (National Health Interview Survey, Dept. of Health and Human Services). Moreover, the Hispanic elderly had, on the average, 37.0 restricted activity days due to poor health in 1986 -- six more days than aged Anglos. Yet the average number of doctor visits for aged Hispanics (8.0) in that year was less than that for older Whites (9.1).

This last fact points out a persistent characteristic of older Hispanics: their underuse of long term care services. Poverty, lack of health insurance, scarce bilingual/bicultural services, language barriers, lack of effective outreach, and, sadly, discrimination continue to hamper the Hispanic elderly's getting such care. This situation persists even though a larger percentage of older Hispanics than older Anglos are functionally impaired and have problems with basic self-care tasks and household management, according to the national survey on "Poverty and Poor Health Among Elderly Hispanic Americans" conducted last year by the Commonwealth Fund Commission on Elderly People Living Alone. That study found that eight percent of the Hispanic elderly have no health insurance whatsoever, compared to only one percent of all older Americans. Medicare is the type of health coverage most often reported by all Hispanic elderly subgroups (49%) except Puerto Ricans (38%). Puerto Rican elderly rely more heavily on Medicaid (46%)

Even though Medicare is the major mode of access to health care for older Hispanics, less than half of the older Hispanic population has it. For them, increases in Medicare supplemental insurance are formidable due to their overwhelming poverty. The threat of a costly long-term illness is all too real for Hispanic elderly and their families. The fact that Medicare does not cover long term care services or preventive services such as eyeglasses, hearing aids and physical checkups presents a major barrier for older Hispanics' receipt of these services.

III. POLICY ISSUES

Changes in the U.S. workforce will greatly affect the availability and quality of long term care for older Hispanics and other elderly Americans in the 1990s. The number of Hispanic women in the labor force will grow by 69 percent (to 2 1/2 million) between 1988 and the year 2000 – more than four times the increase in the total working population (U.S. Department of Labor, 1989). This means fewer family caregivers who can provide long term care to Hispanic elderly at home. For some frail older Hispanics this will be a major problem. Several studies, such as the first national needs assessment of the Hispanic elderly, which the National Association for Hispanic Elderly conducted in 1980, found that few Hispanic seniors live in extended families. Their families furnish emotional support but not extensive financial aid. The Commonwealth Fund study reported that 77 percent of Hispanic elderly who had been hospitalized said a family member or their spouse took care of them, and just 14 percent cared for themselves. Nevertheless it is incongruous for our society to ask the Hispanic family to do what the rest of society does not and cannot do; that is, to stay home to care for an older family member needing long term care. This is an especially unreasonable demand to make of a poor population like Hispanics, all of whose able members must work to survive. And it is noteworthy that despite common misconceptions, the Hispanic elderly do not generally substitute less costly traditional health care, such as use of folk healers (curanderos), drinking of herbal teas, etc., for more costly conventional health care.

Can older Hispanics then rely on in-home care, adult day care, or congregate health services to meet their long term needs: Here, too, the Hispanic elderly confront barriers. Health insurance does not cover many long-term care services. And most Hispanic elderly cannot afford to pay the high costs of long term care themselves.

Civil rights issues are barriers to long term care for some older Hispanics. The middle-class orientation of health care systems, in general, is perceived by many minority groups to be discriminatory in itself, and, hence, contributes to the alienation that many older Hispanics experience when they seek health care (Strauss, 1969; Donabedian, 1972). The perception of discriminatory behaviors may be real or imaginary, but this is irrelevant to the issue. The fact that the perception exists is what determines use of health services. The result of this perception? Older Hispanics forego needed health care.

Stronger civil rights enforcement is required to eradicate discrimination against older Hispanics and other elderly minorities on the part of long term care facilities. Vigorous civil rights enforcement should be carried into the nursing home arena, as well as in employment of long term care workers. This is one of the key first steps that can be taken to meet the minority elderly's long term care needs. Hispanic elderly and other minority elderly will continue to be inequitably served if the doors to congregate care institutions are closed to them.

The number of undocumented immigrants requiring health care continues to increase. These persons face not only language and money barriers, but the specter of ineligibility and deportation if their status is discovered. Even legal immigrants and native-born residents often have difficulty obtaining services because they don't know about them (Lacayo, 1980). There is evidence to suggest that even with outreach, the "neediest of the needy" are not getting information or services.

Speaking little or no English is a primary factor in older Hispanics' lack of knowledge about long term care options. Lack of Spanish-speaking staff, interpreters, material, and outreach in Spanish limit the knowledge of, access to, and use of available services. Redesigning outreach programs to be culturally sensitive and available in Spanish is imperative. Innovative outreach techniques like bilingual radio and television announcement should be utilized to provide information on services like respite care, senior centers, etc. These techniques are especially effective with the Hispanic elderly, for whom radio and television are the preferred communications media.

Yet another barrier to older Hispanics' receipt of long term care is the scarcity of trained professionals and paraprofessionals to furnish such care. Minorities will be an ever-larger share of new entrants to the labor force in the 1990s. Immigrants will constitute the largest share of the increase among workers since World War I. But not only are these groups less likely to have had satisfactory schooling and on-the-job training, they may also speak little English and experience other cultural barriers that prevent them from taking advantage of the booming number of service and health care jobs. The combination of escalating numbers of older people requiring long term care and a poorly educated workforce will be disastrous. A mostly minority workforce will generate the Social Security earnings from which aging "baby boomers" draw their Social Security checks well into the next century. If a large portion of that workforce suffers high unemployment or is locked into low-paying jobs, then the workforce may not generate a sufficient

economic base to sustain the older population in the first half of the 21st century. Unless this country makes a concerted effort now to improving education for minority youngsters and to training young Hispanics and other minority persons for paraprofessional and skilled health care jobs in aging, older Hispanics will continue to be cut off from desperately needed health care.

Retraining mid-life older workers in health care professions is crucial to meeting the need, too. Since 1979 the number of young workers has been declining. But job participation among people aged 55 or over will rise at a faster rate in the 1990s than that of the overall pool of workers. Between 1988 and 2000 more than two million persons aged 55+ will join the workforce. Their experience, stable work histories, high motivation to work, and desire for flexible working hours makes them an ideal group for retraining as in-home health aides and other health occupation.

IV. CONCLUSIONS AND RECOMMENDATIONS

This country must develop a comprehensive community based care system and alternatives to institutionalization as a more balanced approach to meeting the health needs of the minority elderly and other older Americans. Alternatives are particularly important for the Hispanic community, for whom nursing homes ("asilos") are often a dreaded place of last resort when no other health care alternative remains. The system should include in-home and community-based care for the "at risk" aged and disabled persons. This could be achieved by increasing the federal Medicaid match for these services for "at risk" persons if states (1) provide a comprehensive assessment of individuals who probably need long term skilled nursing or intermediate care facility services if in-home or community-based services are not available; (2) provide a wide range of home and community-based services for "at risk" persons who can continue to remain in their communities; (3) establish reimbursement limits at a rate not exceeding the level for nursing home care; and (4) coordinate long term care and community based services provided under other legislation. Assisting elderly Hispanics to become eligible for Medicare or Medicaid should become a top priority. These actions would enable older Hispanics and other elderly minorities to receive more appropriate long term care and in-home services.

The lack of alternative community-based long term care programs that give informal medical and non-medical services (assistance with activities of

daily living) is a persistent problem. Special consideration for the needs of low-income, minority urban and rural older Americans should be taken into account in the design and implementation of such programs. Respite care and home health care, whether available through community agencies, volunteer service groups, hospitals, or nursing homes, will become ever more important because of changes in the employment profiles of younger Hispanics and the availability of informal care.

Ideally, this comprehensive, community-based, long term care system should be incorporated in a national health insurance program. Government funding of home health care and respite care will be required to make these services available to older Hispanics and the other elderly who need them most. Congress must look for ways to improve Medicare to achieve this goal in a fiscally responsible manner.

Thank you again for the opportunity to testify. The National Association for Hispanic Elderly would be happy to supply further information if you wish.