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NCCNHR: The National Consumer Voice for Quality Long-Term Care

"The Nursing Home Reform Act Turns Twenty: What Has Been Accomplished, and What Challenges Remain?"

Senate Special Committee on Aging Senator Herb Kohl, Chairman May 2, 2007

Good Morning:

I am pleased to be here this morning on behalf of NCCNHR to talk about the Nursing Home Reform Law, OBRA '87, which played a particularly meaningful role in our history as the National Citizens' Coalition for Nursing Home Reform. Before beginning my testimony I would like to thank you, Senator Kohl, for your long-time advocacy for higher funding for the ombudsman program and the survey and certification system. NCCNHR also appreciates and supports your efforts to require criminal background checks on those who work with vulnerable long-term care residents, and your efforts to help pass the Elder Justice Act, the first comprehensive legislation since OBRA '87 to address serious neglect and abuse in long-term care.

Twenty years ago, the Nursing Home Reform Law set forth key principles of quality that had been carefully identified in the 1986 Institute of Medicine Report and established them as minimum standards that were to be the foundation of quality of care and quality of life. These standards are now so much a part of long-term care that we tend to forget how truly reforming the law was and how it continues to set forth requirements that are essential to ensuring dignity for our nation's 1.7 million nursing home residents.

Twenty years ago, I was working as a local ombudsman responsible for 12,000 residents in an eight- county area. I was also a member of NCCNHR, supporting its diligent efforts to bring about much needed reforms through a coalition of consumers, providers, unions, and professional associations who labored together to produce a consensus on nursing home reform legislation. That coalition, the Campaign for Quality Care, continues to meet regularly today to support better care in nursing homes. Now, as the Executive Director of NCCNHR, I want to applaud those Campaign participants who worked tirelessly in 1986 and 1987 to ensure passage of the law. Under the leadership of its Founder, Elma Holder, NCCNHR coordinated this national effort to pass federal legislation that set forth standards that would respect each resident, guaranteeing them the care and quality of life that they needed and deserved. The Campaign's work was transformed into law by the fine members of this committee, including Senators David Pryor, John Heinz, and John Glenn, and by Majority Leader George Mitchell.

In the years following the passage of the NHRL, significant changes began to take place in the facilities I visited and across the country. Residents who had been tied to their chairs and to their beds were untied. At the time OBRA was enacted, more than 40 percent of nursing home residents in this country were physically restrained, a magnitude of misery and bad care that would be

¹ American Association of Homes for the Aging; American Association of Retired Persons; American College of Health Care Administrators; American Federation of State, County, and Municipal Employees; American Health Care Association; American Nurses Association; American Occupational Therapy Association; American Psychological Association; Association of Health Facility Licensure and Certification Directors; Catholic Health Association; D.C. Long-Term Care Ombudsman Program; Gray Panthers; Montgomery County Long Term Care Ombudsman Program; National Association of Social Workers; National Association of State Long-Term Care Ombudsman Programs; National Association of State Units on Aging; National Citizens' Coalition for Nursing Home Reform; National Committee to Preserve Social Security and Medicare; National Council on Aging; National Council of Senior Citizens; National Senior Citizens Law Center; Older Women's League; Service Employees International Union; and Villers Advocacy Associates.

unthinkable in most nursing homes in this country today. As an ombudsman, I finally had federal support to advocate for the tiny, frail woman who would weep every time I visited her, "Set me free, set me free," as she stumbled down the hall with the wooden chair she had been tied to on her back. Equally important, residents who were "zombie-like" due to misuse of medications were given the opportunity to be free from chemical restraints that made it impossible for them to enjoy any type of quality of life.

Social workers across the country began to focus on resident rights education as central to their work in facilities explaining that a person does not give up their constitutional rights as a United States citizen when they enter a facility. Mail began to be delivered daily; residents had control of their personal funds; staff were trained to close curtains for privacy, knock on doors and address each resident by the name that the resident wanted to be called. Resident and family councils emerged as voices for improvement in their facilities. Nursing assistants became certified under the new requirement that they have at least 75 hours of training. (It is hard to believe now that prior to 1987, the typical nurse aide began her career with no formal training at all – "right off the street," as we said then. I will never forget the transformation of a nurse aide who had worked in her facility for over 20 years as she earned her certification for learning new skills and, at last, the right way to perform many of the caregiving tasks she had faithfully executed for so long.)

Residents and family members appreciated finally having the right to see the facility's survey (inspection) report and receive a copy of their rights, including the identity and role of their ombudsman. Most important, and central to the entire law, was that care was to be individualized; facilities were to:

Provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of **each resident** in accordance with a written plan of care.

For the first time, care was to be based on an individualized care plan that residents and their family members (if the residents wanted them to) were to be involved in developing with the staff who provided the resident's care.

In the midst of these changes, exemplary providers and strong advocates began developing true models of individualized, resident-directed care. Models that reflected that nursing homes were homes where residents were to be respected by listening to them and basing their care, activities and other day-to-day decisions on what they said defined quality for them as an individual. These providers are now a part of the Pioneer Network, a movement birthed at a NCCNHR Annual Meeting by visionary individuals who are leading the industry from an institutional to an individualized system of long-term care. Their work is demonstrating that it is possible to fulfill the law through *culture change* based on the full involvement of facility residents, family members and workers, particularly the nursing assistants who provide 90 percent of resident care.

Sadly, I cannot report to you today that the expectations and requirements of the NHRL have been fulfilled in the 20 years since its passage. In fact, for many residents, the quality of their day-to-day care is minimal because of inadequate nurse staffing. A congressionally authorized study released

by the Department of Health and Human Services in two phases in 2000 and 2001² demonstrated what our members have told NCCNHR for more than 30 years – there are insufficient numbers of nurses and nursing assistants in the vast majority of America's nursing homes. Daily calls to NCCNHR from consumers and those who advocate with them reinforce what NCCNHR has long held, that no matter how well-trained staff are, how much technology there is for them to work with, how well supervised they are – all important factors – there simply is a limit on how much care a single person can provide. One CNA left a message on NCCNHR's voice mail in the middle of the night, "Can you help me? I care so much about these people but there is only one of me and 24 of them. I am failing them and myself." NCCNHR has actively supported Rep. Henry Waxman's Nursing Home Staffing Act, which would require Medicare and Medicaid facilities to meet the staffing standards identified in the two HHS studies. These reports and other research show that below 4.1 hours of nursing care a day, residents will almost certainly be harmed – suffer from pressure sores, dehydration, malnutrition, fractures, infections, and other conditions that cause pain, decline in functioning, avoidable hospitalizations, and death.

An important dimension of staffing is that residents need more direct care time by registered nurses. A 2005 study demonstrated that increased RN direct care results in fewer pressure ulcers, hospitalizations, and urinary tract infections; less weight loss, catheterization, and deterioration in activities of daily living – all outcomes that residents deserve.³

It is important to pass the Waxman bill, and we hope that it will soon be reintroduced in the House and Senate. There are interim steps that can also be taken, however. CMS has been conducting research for almost a decade on how to collect, audit and report accurate nurse staffing data from payroll records and it has an additional contract to develop nurse staffing quality measures. NCCNHR believes it is time for Congress to tell CMS to move forward on collecting accurate information about every Medicare and Medicaid nursing home's staffing levels and provide this information to consumers, policymakers, researchers, and others who need it. Today, neither government agencies nor consumers can say with certainty what the nurse staffing levels are in most of our country's nursing homes.

NCCNHR is a founding member of Advancing Excellence in America's Nursing Homes, a campaign that includes many of the same organizations that participated in the Campaign for Quality Care to pass the Nursing Home Reform Law. Advancing Excellence is a nationwide campaign among providers, consumers, and those who staff nursing homes to achieve certain voluntary goals, including improving clinical care and addressing workforce issues. NCCNHR is urging every nursing home in the country to participate and to select the workforce goals of reducing turnover and adopting consistent assignment staffing practices that allow nurse aides to work on a daily basis with the same residents, building the personal bonds that improve both the quality of care and the quality of life in the nursing home experience. The standards of the Nursing Home Reform Law cannot be met unless these two workforce measures are addressed by facilities as a part of their quality improvement processes.

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² Report to Congress. Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes, Health Care Financing Administration, Summer 2000, and Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes, Phase II, Final Report, Centers for Medicare and Medicaid Services, Winter 2001.

³ "RN Staffing Time and Outcomes of Long-Stay Nursing Home Residents," Susan Horn, et al., American Journal of Nursing, November 2005.

As the Government Accountability Office has reported today in another of its series of devastating reports on weak enforcement of the NHRL, the law is not being fulfilled for far too many residents due to the failures of our enforcement system that is too often provider rather than consumer focused. Residents and families are not allowed the opportunity to be a part of the dispute resolution process, even though the findings are about their complaints and their care in the facility. Our members tell us that facilities do not pay fines that are imposed for many years, and that in many cases, there are no fines imposed even when care has been neglectful and in some cases had horrific results. Residents tell us that they are frightened to raise their concerns because they are vulnerable and dependent, and family members tell us about retaliation, such as restrictions on their right to visit their loved one, when they attempt to get good care. These pervasive consumer problems are too often not addressed by the enforcement system.

Tragically, what residents, their families and advocates tell us substantiates all the reports by the GAO, the Inspector General, and others: Facilities are allowed to continue in "yo-yo" compliance for years, resulting in severe suffering and sometimes death. NCCNHR documented these "Faces of Neglect" in a book in 2006⁴ so that policymakers would never forget that the faces of those who bear the brunt of poor care are our mothers, fathers, grandparents, friends – in for-profit and non-profit facilities across the country. It must be remembered that these so-called "poor performing nursing homes" are in reality the homes of our elders, the vulnerable, the medically fragile, and those who are near the end of their lives; and it should be noted that in most of the terrible cases of neglect and abuse that are recorded in this book, there was no penalty for the facility or the staff that caused such great suffering and, in most of the cases, unnecessary death. We are asking that *The Faces of Neglect* be included in the record of this hearing as witnesses to the suffering that our system imposes.

The NCCNHR Board of Directors discussed these issues last weekend and agreed that there is serious and great disparity among the states in terms of the nursing home care being provided -- differences in restraint usage, in how sanctions are utilized (and not utilized) to bring about change, in how facilities are inspected and how complaints are handled. This disparity demonstrates a failure of leadership on the part of CMS to ensure confidence that no matter where our parents receive nursing home care, the care fulfills the requirements of the NHRL. CMS could promote quality throughout the country by promoting consistency in inspections and sanctions; using temporary managers so that it is the management of the facility, not the residents, who have to leave when a facility is closed; and by making sure that all states provide consumers the opportunity that providers have to dispute survey findings.

Those who worked to pass OBRA '87 had a great vision – that the federal government has a legal responsibility to ensure that people who live in nursing homes have quality of care and quality of life. That vision has only been partially utilized, but we have the potential to fully implement this law. Many of those involved in the passage of the law will soon need care themselves. Even though our programs and public policy are moving towards more home and community-based care, there continue to be almost 2 million people in nursing homes in any given year for rehabilitation or for long-term care. More and more of us are spending the last days of our lives in a nursing home rather than in a hospital. Those in facilities today are frailer but as isolated and

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⁴ The Faces of Neglect: Behind the Closed Doors of Nursing Homes, NCCNHR, April 2006.

vulnerable as those who were in nursing homes 20 years ago. Those residents are us – the advocates and providers and Congress people who worked for reform years ago, and who now need the protections and the safeguards of the system for themselves, for their loved ones and for all in our society who need long term care.

NCCNHR urges Congress to:

- Support Rep. Waxman's Nursing Home Staffing Act and policies that provide necessary resources for adequate staffing.
- Require CMS to implement administrative procedures to improve nurse staffing levels, such as citing facilities for staffing violations when deficiencies are related to understaffing.
- Require CMS to implement a system to collect, audit and publicly report nurse staffing data and quality measures based on payroll records.
- Pass Senator Kohl's legislation to require criminal background checks on all staff of long-term care facilities who come into contact with residents.
- Pass legislation to address the GAO's recommendations in the March 2007 report, *Nursing Homes: Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents*, and to include new statutory protections for consumers, including protection from retaliation and the right to challenge surveys that do not appropriately address deficiencies experienced by residents.
- Appropriate sufficient funds for the Long-term Care Ombudsman Program to ensure that residents have full access to an ombudsman for complaint resolution and one-on-one consultation.
- Appropriate sufficient funds for nursing home survey and certification to ensure that CMS and state governments are fully staffed and equipped to enforce the law.
- Enact the Elder Justice Act, the most comprehensive long-term care legislation introduced since the Nursing Home Reform Act.
- Investigate ways to hold nursing homes accountable for their expenditure of public funds so that Medicare and Medicaid funds are spent "close to the resident" rather than on administrative costs that benefit the corporation, not the residents.
- Oppose medical malpractice legislation that would deny nursing home residents the opportunity to seek civil justice for neglect and abuse.
- Identify and promote strategies to strengthen the long-term care workforce, including the development of career ladders, mentoring programs, consistent assignment, skilled supervision, and staff involvement in total quality management.
- Promote policies to reduce direct care staff turnover, create a supportive work environment; and ensure adequate living wage compensation, including health care coverage for direct care staff in recognition of the importance of the work they do.
- Identify and promote strategies to implement individualized, resident-directed care in long-term care facilities through culture change.

In closing, NCCNHR would also like to endorse the recommendations of Charlene Harrington.

Thank you again, Mr. Chairman, and members of the Committee for the opportunity to speak for residents, their families, and citizens concerned about nursing home care.