

*Why did a bi-partisan Congress pass and a Republican President **Reagan** sign the Nursing Home Reform Law of 1987? The law requires nursing facilities to “care for its residents in such a manner and such an environment as will promote maintenance or enhancement of the **quality of life for each resident.** The law requires nursing facilities to attain or maintain the **highest practicable physical, mental and psychosocial well-being of EACH resident** according to the written plan of care. The keys are Quality of life and Quality of Care for EACH resident. This is the story of why and how that happened.*

It took two decades of consumer advocacy by residents, family members, ombudsmen and other community advocates across the country to pass this law. The National Consumer Voice for Quality Long-Term Care (formerly the

National Citizens' Coalition for Nursing Home Reform, now referred to as Consumer Voice) made sure residents played a critical role in that advocacy. Consumer Voice elevated the voice of residents at the national level by having Board members who were living in nursing homes and by working with resident and family councils, Ombudsman programs, and other consumer advocates.

This advocacy was triggered in large part by concerns about nursing home conditions. There were exposes of poor care across the country. Federal and state regulations were weak and in some nursing homes, residents sat in clothes soaked with urine and feces, restrained with sheets, suffered malnutrition, died in fires, dehydrated without water, and other horrific conditions received **searing** press coverage. State and Federal Surveyors looked at the charts not the people

being cared for. Residents talked about “Pencil baths” that were documented but not given. .

Congressional hearings were conducted by the Senate Special Committee on Aging and the House Select Committee on Aging in the 1970’s and 1980’s, exposing the abuses. In response **there was a federal initiative in 1978 – 1980,** which sought to strengthen the federal regulations, based on model state regulation. **Some owners said the proposed changes were too expensive...**

In contrast to the reports of poor care and attempts to weaken regulations and oversight, there was evidence that good care and an effective regulatory system were achievable.

The Consumer Voice and 43 national organizations and individuals issued, A
Consumer Statement of Principles for the Nursing Home Regulatory System,
in 1982.

**In addition, a lawsuit, *Smith v. Bowen*, in Colorado spurred government action
when the federal court in Denver ruled that the Department of Health and
Human Services had failed in its duty to assure quality of care for Medicaid
residents of nursing homes.**

**In response to the poor care and regulatory impasse, Congress in 1983
commissioned an Institute of Medicine (IOM) study on nursing home regulation
that was funded by the Centers for Medicare and Medicaid Services (CMS,
formerly HCFA – the Health Care Financing Administration) . The Consumer**

Voice published, *A Consumer Perspective on Quality Care: the Residents' Point of View*, as part of the IOM study. This seminal work brought the residents' voice to the national discussion of quality care in an unprecedented way.

In 1986 when the IOM report, *Improving the Quality of Care in Nursing Homes*, was released, the Consumer Voice seized the moment to get the recommendations enacted into law.

Elma Holder, the Founder of the Consumer Voice, launched the Campaign for Quality Care (CQC) in response to the publication of the IOM report.

The CQC brought together national organizations representing consumers, health care professionals and providers to work together to develop consensus papers on major issues. The one exception was PASARR which was developed

independent of the Campaign by national organizations representing individuals with mental illness and persons with intellectual disabilities.

What were the some of the major CQC consensus positions and how were they

achieved? Issues included Resident Rights, Strengthened Ombudsman

Program, Comprehensive Uniform Resident *assessment and care planning*, nurse

aide training, Social services, an end to Medicaid discrimination and facility

closures without notification.

In an intense year of weekly subcommittee and monthly meetings

with 22 national organizations, CV's CQC achieved Consensus on the

major IOM recommendations. Minority papers on important issues

without consensus like RN staffing were included in the final report

presented to Congress. .

The CQC relied heavily on the experiences of effective state regulatory systems, the good care practices of committed staff in hundreds of nursing homes, and the advocacy experience of state and local ombudsman programs as well as other advocates and nursing home residents.

Organizations such as the National Association of Activity Professionals, the National Association of social Workers, the American Psychological Association and the American Nurses Association, shared best practices with the CQC.

In, 1987, the Consumer Voice presented the CQC's consensus statements to Congress during a session hosted by Senator David Pryor who helped craft the landmark nursing home reforms.

In order to encourage passage of the 1987 law, The Consumer Voice guided and supported a national advocacy movement and sustained a grass roots campaign to ensure Congressional support.

At the same time, Congressional sponsors held hearings where national organizations and academics with evidence based research testified in support of the Campaign's consensus positions.

With bipartisan support, Congress passed the Nursing Home Reform Act and it was signed into law on December 22, 1987!!!

Although the law is not perfect, it contains ground-breaking provisions that remain important to individual residents. Other panelists will discuss important impacts of the law, areas where improvements are needed, and how each of us

can continue to work to improve care for everyone in long-term care. Achieving the law is a testament to the strength of tenacious advocates. **Implementing, preserving and strengthening its provisions have and continues to require the same vigor and focus.** Dr. William Scanlon, then director of Health Financing and Public Health Issues at the General Accountability Office, said before the Senate Finance Committee in 2003, holds true today, and I Quote **“But we must not confuse a wish to improve quality in all homes with the more pressing need to ensure minimum quality of care in every home, to eliminate the possibility that nursing home residents can be at risk of harm, due to woefully deficient care.”**