

## ***Consumers and advocates give voice to their experiences and opinions on OBRA.***

NCCNHR thanks them for giving permission to share their insights in what we hope will provoke national discussion on how to improve the resident experience.

*“Let us tenaciously face the difficult, but rewarding, unfinished work to bring about resident-centered care based on solid knowledge, effective strategies and gracious leadership intent on influencing enduring change.”*

*~ Elma Holder, NCCNHR Founder*

1. What are the most significant changes you have personally witnessed/experienced since the Nursing Home Reform Law was passed in 1987?
  - The use of care planning seems to be the most noticeable difference; at least facilities are required to assess and then develop plans for residents. The downside is that computerized care plans have been developed and facilities use them as templates to do pro forma planning. We have found that detailed, resident-centered care planning often requires the involvement of empowered consumers and/or ombudsmen. Restraint use has been reduced significantly. Even so, the assessment of residents for the appropriateness of restraints doesn't meet the vision. Residents who want a side rail for bed mobility are not allowed to have them. "The state won't let us," is the refrain. Other residents are restrained without assessment or a plan for reducing restraints because, "the family wants this and they signed a waiver of liability." Medication use and review is another positive aspect of the reform law. The monthly review of meds by the pharmacist has been good for residents and for reducing negative medication interactions. The survey process has improved also. The contact with ombudsmen has vastly improved over time with our input at least being considered in the survey. The guidance portion of the regulation (42 CFR §483.10...) has had enormous benefit to ombudsmen as they work with consumers and with regulators. Knowing the intent of the regulation has helped us advocate for the resident.

*~ Kathy Gannoe, Nursing Home Ombudsman Agency of the Bluegrass, Inc. Lexington, KY*
  - During the late 1980's Ginny was "pushing for raising resident's rights and quality of life to a "condition of participation", advocating on the state level for licensure of assisted living, training of nurse assistants and promoting the Ombudsman program." Virginia shares, "My Annual Report of 1988 stated: At the most basic level, where improvement is really needed are the issues of people not getting

help when they need it, call lights not being answered promptly, residents not being taken to the bathroom when they need to go, staff not having a few extra moments to spend in friendly visiting with the residents. We must find a way for residents and families to raise issues of concern without fear of retaliation. We must find a way for the system to reward those nursing homes that focus on rehabilitation. We must make nursing assistant training mandatory. We must have more community involvement in nursing homes. We must hear more laughter.”

~ *Virginia Fraser, Colorado State Ombudsman when OBRA was passed; co-author of Nursing Homes: Getting Good Care There.*

- The most significant change that positively affected dignity, privacy and quality of life was the rule requiring no less than 80 square feet per person of living space. Up to that point there was human warehousing which increased industry revenue with little regard for the person or challenges for the staff caregivers. However, since that 80 square feet has the person's bed, chest, chair, bedside table and any durable medical equipment they need on it; with another person's 80 square feet next to them separated by a thin curtain - well, the quality of life and care for both is still somewhat of a challenge. “I began my long-term care career in 1988 and witnessed the implementation of the NHRL first hand as an employee of a long-term care facility.”

~ *Patrice Berry, Regional Ombudsman, AAA of Ark-Tex, Texas*

- As for myself, I believe the most significant changes are directly related to the reduction in physical and chemical restraints. I was a nursing home social worker for 10 years beginning in 1984. At that time ALL residents were subjected to some kind of restraint, usually for the convenience of the staff. It is very gratifying to know that the use of physical restraints and chemical restraints must be the least restrictive and for a specific problem, not just because.

~ *Dianne Brookins, LTCO Coordinator, Georgia Mountains Long Term Care Ombudsman Program, Gainesville, GA*

- We don't see people “tied up” like we used to in the years before OBRA 87. While we still have work to do in making homes restraint free, the situation has greatly improved.

~ *Joseph Rodrigues, State Long Term Care Ombudsman, Office of the State Long-Term Care Ombudsman, Sacramento, California*

- The most significant change is the new survey procedure, QIS, even though it merely forces stronger compliance with the original regulations.

~ *Deanne Bacco, Executive Director, Kansas Advocates for Better Care*

- Thank God for NHRL. If not for that, nursing home care, even in a progressive state like Massachusetts, where my dad was a resident of a

nursing home for the last 33 months of his life, would be far worse. That law is the most important tool that nursing home residents and their advocates have.

~ *Kevin Eddings, Chair, Council of Family and Friends of the Center for Extended Care at Amherst, MA* (Kevin moved to where his father was living and spent each morning with him. He and his mom formed a family council to address those concerns common to all residents.)

## 2. What vision/expectation did you have for OBRA that has not been fulfilled?

- I had hoped that care would truly be individualized. The spirit of the law is terrific—individual assessment and then individual care plans. However, in the interest of expediency, this has been reduced to a cookie-cutter process unless consumers and/or advocates become involved. I had also hoped that the spirit of the law would have been embraced by all staff. I have found that it is a rare joy when staff truly implement the law. Since the culture of a facility seems to flow from the top down, I expect that the real problem lies with owners and administrators. For many of them, it has been business as usual. Even when corporate level staff state support for the law, it seems to dissipate by the time it reaches the level of the actual resident. This isn't 100% true, there are some sterling examples of owners et al embracing the spirit of OBRA.

~ *Kathy Gannoe, Nursing Home Ombudsman Agency of the Bluegrass, Inc. Lexington, KY*

- An unrealistic expectation was to believe that elder persons would be treated with utmost courtesy and kindness regardless of their medical condition or payment type.

~ *Patrice Berry, Regional Ombudsman, AAA of Ark-Tex, Texas*

- OBRA is still viewed as a "compliance issue". I expected the owner/operator to use OBRA as a catalyst to change how care and services were delivered. All regulations are minimums, but rarely does any home go above and beyond the minimum.

~ *Dianne Brookins, LTCO Coordinator, Georgia Mountains Long Term Care Ombudsman Program, Gainesville, GA*

- I don't believe we've come as far as we should in making homes *real* homes. For the most part, nursing homes still look like hospitals. There is an institutional feel to them. People live on a schedule, and it's not their own.

~ *Joseph Rodrigues, State Long Term Care Ombudsman, Office of the State Long-Term Care Ombudsman, Sacramento, California*

- OBRA has not done a good job of requiring adequate nursing staff hours, rather than minimum nursing staff hours, which NFs use as the “standard”.  
~ *Deanne Bacco, Executive Director, Kansas Advocates for Better Care*
- There is still not “quality of life for residents of NHs”.  
~ *Pat Engelhardt, Citizens for LTC, Delaware*
- The regulations are great, intended to serve the needs of the residents, obviously a highly vulnerable population. Yet I quickly learned that.....there are many good laws on the books, but few are enforced. It has been difficult to have even what we feel are serious and obvious violations of those regulations come to the attention of the Department.  
~ *Kevin Eddings, Chair, Council of Family and Friends of the Center for Extended Care at Amherst, MA*

### 3. What needs to be done to more fully implement the NHRL?

- I think that the culture change movement is helping implement the NHRL. It needs to be supported and encouraged. I don't think reimbursement is a barrier although that is often cited by providers as a barrier to true individualized care. The survey agencies need to fully embrace the concept and be willing to use the sanctions available to them. The carrot has been used (at least in our state) but the stick is often applied unequally. Also, facilities which truly embrace individualized care can be sanctioned by surveyors who look at facility life too narrowly. This is particularly true in the area of autonomy and choice. Ironically, autonomy and choice are cornerstones of the NHRL.  
I think that the most troubling aspect of the NHRL implementation is its unevenness. In my area we have facilities which wholeheartedly embrace the spirit and the law and then abandon it when there are changes in the staff. Other facilities act as if they never heard of it. Then, we have the shining lights where all of the lead staff have bought into individualized care, resident choice, homey environments. It is a joy and a privilege to work with these providers. My favorite facilities are those who respond to consumer concerns with, "I sure am sorry that happened. I'll get right to work on fixing this and report back to you." I think that attitude exemplifies OBRA.  
~ *Kathy Gannoe, Nursing Home Ombudsman Agency of the Bluegrass, Inc. Lexington, KY*
- \*Impose minimum staffing levels according to the guidelines researched and suggested by NCCNHR. Basically, no less than 1 direct caregiver (Nurses Aide) per 8 Nursing Home residents. \*Persons who wish to enter THE medical field (esp. RN's and PHD) must - during some portion

of their training - have 30 DAYS clinical experience caring for elders in the Nursing Home setting as a Nurses Aide. \*Strengthen state regulatory/enforcement and eliminate the ability for facilities to appeal on-site findings from the regulatory/enforcement state licensure survey teams and implement a three strike rule based on those findings. \*Do not allow any U.S. long-term care facilities (Nursing Homes or Assisted Living or Adult Foster Care) to operate **unlicensed** 'special care', 'locked', units for persons with dementia. \*Regulate Assisted Living Standards and rights for the people who live there, nationwide.

~ *Patrice Berry, Regional Ombudsman, AAA of Ark-Tex, Texas*

- CMS needs to encourage more facilities to make that joyful journey from institution to community.  
~ *Joseph Rodrigues, State Long Term Care Ombudsman, Office of the State Long-Term Care Ombudsman, Sacramento, California*
- To more fully implement the NHFL, nationally regulate the true minimum nursing staff hours that are required nowadays.  
~ *Deanne Bacco, Executive Director, Kansas Advocates for Better Care*
- The single most important thing Congress can do to improve the quality of care in nursing homes is to improve enforcement of federal regulations that govern them, improve oversight, make it easier to sue homes and state oversight agencies for lack of enforcement, and allow monetary damages to be awarded for homes that violated regulations and oversight agencies that don't enforce them.  
~ *Kevin Eddings, Chair, Council of Family and Friends of the Center for Extended Care at Amherst, MA*

**4. Were you involved in the passage or implementation of OBRA '87? If so, how?**

- Yes. I was invited to D.C. to participate in discussions about the details of the law. My involvement was supported by AARP. I was also on the NCCNHR board at that time and contacted local legislators. My staff has been trained and retrained on the NHRL over the years so that they can educate both consumers and providers about the law. I have written about the law for the media and spoken about it before a number of groups.  
~ *Kathy Gannoe, Nursing Home Ombudsman Agency of the Bluegrass, Inc. Lexington, KY*