

Minimum Staffing and
Long-Term Care
Monitoring
page 3

About the Maryland
Board of Nursing
Home Administrators
page 4

Discriminatory Nursing
Home Regulation
From the Chair
page 6



NEWSLETTER VOICES FOR QUALITY CARE

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Click for Articles: [URLs on bottom of Page 7](#)

Overcoming Barriers to High Functioning, Independence & Community

By Penelope Shaw

Penny Shaw is a member of Voices for Quality Care

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After an acute non-resolving episode of Guillain-Barre syndrome in 2001, being in an ICU not expected to live, and a year in a respiratory rehabilitation hospital, I was transferred to a nursing facility where I have been living for 16 years. Due to the residual effects of my illness I have quadraparesis —muscle weakness in all four limbs. For five years I had a tracheostomy and a feeding tube, both of which were successfully removed in 2006. I am today "total care."* I would like to live in the community, but am unable to do so, because of my need for access to 24-hour care, which MassHealth [Massachusetts Medicaid] does not provide.

I would spend nine-and-a-half years inside medical facilities, before regaining my independence and reintegration into the real world in 2011.

Mine is a story of good staff and good care, but also of barriers to escaping institutionalization, and being able to freely be my own person — low expectations, unnecessary drugs, paternalism, policies with no basis in law, and even design problems.

Low Expectations

Unlike in the rehabilitation hospital where I got up, participated in activities, did watercolors, went outside in nice weather and had a friendly visitor to talk to, I was mostly bed-bound in my facility for several years. I read non-fiction and scholarly books. A CNA assumed I was only turning the pages, and offered me a picture book instead. Once, when I tried to talk about a book I was reading to a staff person, she asked if the words I was saying were words. Intellectually, I was isolated among the direct care workers.

I knew a woman in 1990 who used a wheelchair, while simultaneously being on breathing support. Nothing like that was suggested to me by the rehab staff in my building. It was not until 2010 at age 67, when I was outside at a medical appointment, that a clinician asked why I didn't have a power chair. So, I got one, which transformed my life by providing me with mobility and freedom. The failure to understand the importance of assistive technology denied me many years of enjoying life in the community.

I was amused as my advocacy became well-known, that I was told, "We just thought you were a nice person," confirming my belief that little had been expected of me.

(continued on page 2)

Paternalism

Institutions can be paternalistic and disempowering, but I fought back against this. I suffered from infantilization, staff patting me and calling me “boo-boo” and “baby.” I had to ask for my name back. A phlebotomist, obsessed with the fact that my neck weak on the right caused my head to tilt, wouldn’t stop trying to fix the problem. So, I went outpatient for bloodwork to get away from her. I encountered paternalism when a staff person was obsessed in summer, that I neither used sunblock nor a sun hat, and when a physician who had forgotten the federal Patient Self-Determination Act, repeatedly pressured me to change the insulin I’d been using for years without incident. Both thought they were acting in my best interest. I ignored the woman, and chose my own physician, now going outpatient for primary care to avoid boundary violations.

The paternalism I continue to deal with is resistance to resident-direction, the belief of some CNAs that they, not me, are the experts in my care routine. Offended when I direct them, they tell me how many years they’ve been a CNA, unaware of the importance of lived experience. I respond that each resident is unique, that I know the most efficient and correct way. Alas, CNAs have been trained to do tasks — wash, dress, transfer, but not to be curious and ask questions. One of my favorite CNAs and I banter back and forth about this. She says, “You can’t do anything for yourself,” implying therefore she has the right to decide what care I need. I just insist on the routine I want, my right to do so supported by federal regulation as person-centered care.

Unnecessary Drugs

In 2010, I went to a resident council meeting where an ombudsman gave me a booklet listing some of the nursing home residents’ rights. I learned I could read my medical record, which I thought would be interesting. I discovered that I had many wrong diagnoses, and was being given inappropriate drugs crushed in applesauce — psychosis “Not Otherwise Specified” [Geodone], depression [Prozac], pain [Oxycodone], GERD [Prilosec], edema [Lasix], insomnia [Ambien and Trazadone]. Knowing these were all incorrect, I discontinued them that day. No apology was ever forthcoming. This was the beginning of my real recovery — thinking and questioning seriously about where I lived, what was going on, challenging the system by speaking up and managing my own care.

As a survivor of psychoactive drug misuse, I was pleased to have the opportunity to consult on, and to be named in the acknowledgments of, the Human Rights Watch 2018 study on the misuse of antipsychotic drugs in nursing homes, *[They Want Docile: How Nursing Homes in the United States Overmedicate People with Dementia](#)*.

Policies Without Basis in Law

I had to challenge a couple policies to promote my independence. When my power chair was being charged in a room down the hall away from the room where I sleep, numerous times I had insufficient power to go out, as the batteries had not been charged. I researched the laws regarding having my chair charged in my room, and discovered this didn’t violate fire or building codes, and was already happening in other facilities. I now have my chair charged where I can see if it’s actually being done properly. I also had to use my rights to insist CNAs safely move my chair manually, as the controller is not designed to be used from a standing position.

About the Author

Penelope Shaw is an older adult — 75 — with a disability who lives in a nursing home. Despite her disability, she has pursued a career as an educator, writer, disability advocate and advisor. She has become a respected voice for people with disabilities in the Boston, MA area and beyond. She testifies at committees of the Massachusetts Legislature, appears in local TV and radio news broadcasts, and interviews by The Boston Globe, the Braintree Forum, and the Associated Press. She is a professional writer, having published in peer-reviewed scholarly journals, newsletters and blogs. Her writing appears in an advocacy book, and on advocacy websites. The Administration for Community Living recognized her advocacy efforts by designating her an elder trailblazer for Older Americans Month 2016. She is affiliated with a wide range of policy-making bodies including the Disability Policy Consortium, the Massachusetts Executive Office of Elder Affairs, the Massachusetts Advocates for Nursing Home Reform, the Museum of Fine Arts, the Massachusetts General Hospital and the Institute for Human-Centered Design.

Ms. Shaw has a PhD in French Language and Literature with a specialization in psychology and literature. She taught French for several years, but most of her career she was an English Language Learning faculty member and administrator. She worked at the University of Michigan Ann Arbor, the College of the Virgin Islands/Peace Corps Training Camp, the Instituto de Estudios Superiores in Santo Domingo, Dominican Republic and in the Boston area — Boston University, UMass Boston and the Kennedy School of Government, Harvard University.

(continued on page 5)



Considering Nursing Home Minimum Staffing Levels

Numerous studies and reports on minimum staffing levels in nursing homes have found that good care requires at least **4.01 to 4.13** hours of care daily. This is a minimum level of care for every person living in a nursing home regardless of acuity. Clearly, there are many people living in nursing homes that require a higher level of care.

In Maryland, the required minimum staffing level remains at a dismal **2.0** hours of care per resident per 24-hour day. The one staffing ratio for Maryland nursing homes requires that the ***“ratio of nursing service personnel on duty to patients may not at any time be less than one to 25”***.

218 Maryland nursing homes were listed in the Center for Medicare & Medicaid Services (CMS) Payroll-Based Staffing Data Download for the first quarter of 2018 (January 1, 2018 – March 31, 2018). Of those

- 67 (30.88%) show patterns of low staffing on weekends**
- 10 (4.61%) of the 218 had some days under the required 2.0 hours of care per resident per day**
- 8 (3.69%) had at least 4.0 hours of care daily in the 1st Quarter of 2018**
- 78 (35.94%) had at least 3.0 hours of care daily in the 4th Quarter**

In the District of Columbia, the required minimum staffing level is a robust **4.1** hours of care per resident per 24 hour day. There is a waiver available, however, that may allow staffing levels of 3.5 hours of care per resident per day in certain circumstances.

14 Washington, D.C. nursing homes were listed in the Center for Medicare & Medicaid Services (CMS) Payroll-Based Staffing Data Download for the first quarter of 2018 (January 1, 2018 – March 31, 2018). Of those

- 6 (43%) show patterns of low staffing on weekends³.**
- Three (21%) had at least the required 4.1 hours of care per resident every day in the first quarter of 2018.**
- Two (14%) had an average of less than 3.5 hours of daily care**

Minimum Staffing Requirements in Nursing Homes

Delaware Requirements are User-Friendly

In Delaware, minimum staffing levels in nursing homes was accomplished by law rather than the Maryland practice of using just regulations for this purpose. The Delaware Law requires specific ratios for minimum staffing levels for each wing, unit, or floor and for each shift. This allows residents, families, surveyors, and ombudsmen to know immediately whether or not any given unit is in compliance with those state legal minimums.

Maryland and D.C. Requirements are Not User-Friendly

In Maryland and in the District of Columbia, staffing levels are still determined by counting staff in the entire building for a full 24-hour period making it impossible for anyone to determine whether a nursing home is in compliance with state regulations in any unit on any particular shift. Proposed new regulations for Maryland Nursing Homes, which have been “in the works” for many years now with little progress, do not address this unwieldy method of counting staff.



Voices Reports a Neglect of Long-Term Care Monitoring Services

Levels of staffing in Maryland nursing homes point to a risk of harm while issues in assisted living facilities remain sincerely troubling. Yet the three sources of monitoring these facilities, the Office of Health Care Quality (OHCQ), the Long-Term Care Ombudsman Program, and the Oversight Committee on Quality of Care in Nursing Homes and Assisted Living Facilities are currently **not** in compliance with all aspects of the laws and regulations governing their operations.

- OHCQ is paralyzed by a lack of funding.**
- The Ombudsman Program is paralyzed by lack of staff.**
- The Oversight Committee is paralyzed by lack of will.**

Voices Recommends

- A robust increase in staffing for OHCQ
- An increase in the Ombudsman Program staffing including at least a part-time dedicated attorney and additional staff in the Office of the State Ombudsman as well as full staffing at the local Ombudsman program levels.
- Ensuring that the Oversight Committee includes sufficient support staff to enable it to effectively **evaluate** services in long-term care facilities and to make **recommendations** for improvements.

About The Maryland State Board of Examiners of Nursing Home Administrators

by Rhonda Washington-Butler, MPA

The Maryland State Board of Examiners of Nursing Home Administrators (“BENHA”) was formed in 1970 and is required to exist and operate, per Federal statute and regulation (see U.S. Code, Title 42 § 139g and Code of Federal Regulations, Title 42, Part 431, Subpart N). BENHA’s mission is: “To protect the citizens of Maryland and to promote quality health care in the field of long term care by: 1) Licensing and certifying nursing home administrators; 2) Receiving and resolving complaints from the public, courts, employers, insurance companies, other licensees regarding nursing home administrators who may have violated the Board’s law (Annotated Code of Maryland, Health Occupations Article, Title 9) and its regulations found at COMAR 10.33.01; and 3) Setting standards for the practice of nursing home administrators that reflect new and emergent developments in the practice of long term care through regulations and legislation.” BENHA’s vision is: “A state that provides citizens qualified nursing home administrators to further the good health and well-being of the citizens of Maryland.”

BENHA works in conjunction with the Office of Health Care Quality (“OHQC”), which regulates the nursing home facilities where licensed nursing home administrators practice, to maintain the highest standards of care for residents of nursing homes. OHQC regulates the approximately 233 nursing homes in the state. There are currently 520 active nursing home administrators in Maryland, and 18 candidates in active Administrator-in-Training programs. During the 2015 Maryland General Assembly session, BENHA’s termination date was repealed because it was deemed by the Department of Legislative Services to be functioning well in fulfilling its mandate and because allowing BENHA to sunset would jeopardize approximately \$571 million in Federal funding for Maryland’s nursing homes.

Recent legislative and regulatory changes promoted by BENHA are as follows: 1) Health Occupations Article § 9-302.1 became effective on October 1, 2016. This law requires all licensees and applicants to undergo a one-time criminal history records check. This served to help the Board continue to protect the citizens of Maryland; 2) COMAR 10.33.01.14 was amended, effective February 27, 2017 to allow Executive Directors of CCRC’s to serve as preceptors to Administrators-in-Training who are trained in nursing home facilities that are on the same property as the Executive Director. This provided extra flexibility to licensees; 3) Health Occupations Article § 9-301 was amended, effective October 1, 2017, to include a requirement (at § 9-301(b)(2)(ii)2) that provisional licenses be issued to non-licensed persons when they are appointed to serve as interim administrators under unexpected, emergent conditions in which an LNHA is unable to be immediately appointed; BENHA is discussing other legislative and regulatory changes in the near future.

BENHA is a member of the National Association of Boards of Long Term Care (“NAB”) and actively participates in NAB’s Annual and Mid-Year Meetings. This allows for active and ongoing collaboration with other states and helps BENHA to maintain a national presence and stay informed of industry changes and best practices.

The current Board Chair of BENHA is Felicia W. Anthony, MPA, LNHA, and the current Executive Director is Ronda Butler Washington, MPA. Detailed information about BENHA may be found at <https://health.maryland.gov/bonha/Pages/index.aspx>

Maryland Licensing Boards

There are several licensing boards in Maryland tasked with setting standards, certifying, and resolving issues and conflicts with various health care personnel. Among those are the Board of Dental Examiners, the Board of Physicians, Board of Nursing, and the Board of Examiners of Nursing Home Administrators.

All of these Boards accept and investigate complaints regarding the professional conduct of any of these healthcare officials.

For additional information and contact information for a healthcare board, go to

<https://health.maryland.gov/Pages/>



Is there a way to change the culture of nursing homes? Yes, says Beth Baker, author of "Old Age In A New Age". Demand a new way that people can live in old age. Challenge the acceptance of the traditional institutional model. Advocate for change to home-like places that honor the individual and community.

Overcoming Barriers to High Functioning, Independence & Community

Continued from Page 2



A rehab person informed me of a new corporate policy, that I would no longer be allowed to keep the Roho cushion [state-of-the-art] on my power chair, but would be provided another cushion instead. Rohos are most protective of pain and pressure ulcers, which are common in users of wheelchairs. I questioned, and found that there was no recall of the cushions, and learned as I'd suspected, that there'd been an incident in a facility where staff had not kept the Roho properly inflated, causing a wound. I let my administrator know the chair and cushion are my personal property, not of either our facility, nor of our corporate owner, and that I was keeping it to be comfortable, especially in long van rides in the community

I was told after years of doing so, that I could not have anyone but a nurse or CNA put a sweater or jacket on me. This meant I might waste as much as a half hour before going out, navigating busy elevators up to my unit and back, and to find an available staff person. I checked and was told that anyone can dress me, because all staff in my building have liability insurance and also, that the licenses permitting nurses and CNAs to dress me are not restrictive.

Design Problems

Solving problems with designs that don't work as they should has been essential to my independence. An unpadded reclining shower chair made of hard PVC was extremely painful to lean on, and would have discouraged me from having showers to be clean enough to go into the community. I had CNAs put heavy blankets on the chair to make it comfortable. As is common for those of us who are not weight-bearing, we often develop kidney stones due to poor circulation. Drinking six 16-oz cups of water daily is preventative. But when the lids of the cups our central supply was getting us had only side-of-lid openings for straws, this would have allowed water to pour all over me. I went to the hardware store and bought a small \$2 breakaway knife, with which I create holes in the tops of the lids. This helps keep me out of the hospital and able to go into the community.

The most serious design problem I encountered was when the loops of the lift sling I used were starting to fray, making the sling soon unusable. I had my facility buy a new sling — same company, same design, same size, only to find a disastrous design change. The "hand holds" in the back of the sling to pull me back, and position me properly in my chair for comfort, were 6" lower than on my current sling, causing staff to have to let go before completion of a proper transfer. I could not go out positioned like that. I contacted our supplier and the manufacturer, both unsuccessfully, and found that a colleague who knows the "textile people" in the disability community was out of the country. Thinking I might have to have a requiem for a sling, as I might have no more independence, it finally occurred to me to take two of the same slings to an upholsterer. I had him remove the band with the holds from one sling, and attached it at the right height on the other sling, without affecting in any way the integrity or safety of the sling.

Finances

An unresolved barrier to full participation in society for nursing home residents on MassHealth, is the low personal needs allowance of only \$72.80 monthly, which has not been increased in 10 years. There is an assumption that nursing home residents don't

need much — not transportation to get to places they want to go, nor decent clothes to be presentable in public, nor a working cellphone for safety — all of which residents are responsible for paying for themselves. So, it is often state governments which block the doors to the outside.

Community

After years of being inside walls, I reintegrated myself into the community incrementally. I now have an ordinary life. I manage my care and personal life — making appointments and transportation for medical, dental, advocacy and leisure activities. I have a cellphone, use the internet, have an account with a debit card at a bank in my neighborhood, go shopping, go to the farmers' market, eat out with friends, take classes, go to the beach and conservation areas. I belong to a writers' group, vote at my polling place, visit museums, march in my town's Fourth of July parade and go to the library to attend special events.

I also became an advocate, first a nursing home one, then a disability one. I became increasingly asked to participate in many advisory ways.

I testify at committees at our state legislature. I speak at government offices, my town council, and at professional meetings of academics and aging service providers. I consult, am in the news and publish in scholarly journals. I do access tours, and have worked as a user/expert with design students at several Boston-area colleges and universities, on development of adaptive devices for individuals with physical disabilities.

I do not consider myself institutionalized, but community-dwelling, actively engaged socially, intellectually and civically. I am continuing the meaningful roles, social relations and lifestyle I had before paralysis. Being outside my facility, I am not isolated from my community. I have normalcy, critical to my self-worth and personhood.

Conclusion

There are a thousand reasons not to live in a nursing facility. Facilities can inhibit independence and community integration, as they are complex organizations of people of varying skills, personalities and experiences. I do not think it is possible for staff to predict what each resident is maximally capable of. So residents and their representatives need to make requests, advocate, and fight relentlessly against obstacles, sometimes just saying "No!" Although no one intentionally kept me inside and made me a prisoner, that would have happened had I not been empowered and solved problems each step along the way. In my particular case, the management of my facility is supportive of my life in the community by partnering with me. They do this with a schedule that makes my life predictable, by having working lifts and internet access, and by paying for private transportation to speak at a conference. They also support me by valuing my work, with a framed picture in our reception area of me as an advocate, on the front page of the Boston Globe.

* "Total care" is a billing term under skilled nursing care meaning my functional needs approach total. I need to be washed, showered, dressed, positioned, transferred.

Discriminatory Nursing Home Regulation

The Regulation: 10.07.02.27 Pharmaceutical Management

D. (5) The pharmacy shall be responsible for delivering medications to the facility. Members of the resident's family or the responsible party for the resident may not deliver medications to the resident or to the facility.

This is a regulation that Voices has been concerned about for many years. The regulation applies only to the family members and sponsors of people living in nursing homes. It does not apply to a family friend or neighbor, a stranger walking past the pharmacy door, or the local drug dealer. It prevents families and residents from using mail-order prescriptions. It prevents families from obtaining prescription and over the counter medications from sources such as Costco, Walmart, etc. that are, in many cases, far cheaper than those provided by the institutional pharmacies. It is discriminatory toward family members, sponsors, and residents wishing to exercise their federal rights to choose their own pharmacy. It exists only in Maryland.

A Personal Story

Correcting the regulation as to a choice of pharmacies, and as to family members having the option of delivering medications. At the time my mom entered the nursing home for a long-term stay, I had just spent \$400+ for her monthly supply of medications because she had capped out under Kaiser. I was not allowed to leave those medicines with her upon her admission to the nursing home. So, an extra expense was incurred by the nursing home because they were then given the responsibility to care for her, and to ensure that she had the medications needed for her well-being. Because I could not return the unopened medications I purchased to the pharmacy, I had no choice but to trash \$400 worth of medications, which had been an expense that was outside of my budget.

From the Chair -

It was around the year 2002 that four people decided upon a specific mission, i.e., to challenge the accessibility of, and the quality of health care in long-term care facilities; specifically, in St. Mary's, Charles, & Prince George's Counties, Maryland. The mission of those four individuals resulted from their personal family experiences in dealing with long-term care services in nursing homes. Without knowing what the future would present, those four committed themselves to advocating, not only for their loved ones, but for others as well.

The mission and vision of Voices for Quality Care (LTC), Inc. was defined at its inception, and it is still ongoing. Over the years, Voices experienced name changes, members coming and going, statewide expansion, and a changing of the guard so to speak. Nevertheless, Voices' progression, and its strength has been complemented by the support of loyal and dedicated members in addition to its relationship with various outside stakeholders. Thus, this edition of our newsletter is in honor of those Board members, and supportive members who tirelessly paved a way, and those who continue to stand strong with Voices today.

Although there are still tasks to be accomplished, throughout the years Voices' position remains the same-- uncompromising and unyielding. We will continue educating the public about and advocating for the need of quality long-term care services until our vision becomes a reality. With this being said, Voices invites each of you to continue accompanying us on this journey. And, remember, one voice is heard as a whisper; but a thousand voices are heard as a roar!

—*Jaqueline Anderson*



And now, unfortunately, the commercial...
We really do need your help to continue our work!

All Voices work from advocacy to individual help is done entirely by volunteers and all of our services are free. We have no paid staff.

Please donate @

<http://voicesforqualitycare.org/donate/>



The Helplines

Our Toll-free Phone Helpline can be accessed at 888 (600) 2375.

The email helpline can be accessed at voiceshelp@voicesforqualitycare.org

All helpline emergency requests for assistance are answered immediately 24 hours a day, 7 days a week.

All non-emergency communications are answered within 24 hours.

These calls and emails include requests for assistance in emergency and non-emergency situations, requests for long-term care information, reports of low staffing, poor care, or dangerous conditions in specific long-term care situations.

Wonder how we will use your donation?

- *A gift of any size will help us create and run the Excel Visual Basic software package needed to organize and define the new CMS Payroll-Based Staffing data.*
- *A gift of \$120 will support the hosting of our web site for a year.*
- *A gift of \$60 will pay for a month of the answering service.*
- *A gift of \$30 will support our 888 phone number for a month.*
- *A gift of \$10 will pay for the post office box for a month—\$120 will pay for it for a year.*

Proposed Payroll-Based Staffing Software

The Center for Medicare & Medicaid Services (CMS) has finally begun posting nursing home staffing levels for nurses & nurse aides based directly on payroll data rather than the unchecked facility -provided data used in the past. This gives us a much more accurate picture of the daily staffing levels in these facilities.

However, as posted on CMS, it is basically a 3 month long list of numbers that are difficult to sort based on important aspects such as low week-end staffing, days staffing falls below required levels, excellent staffing levels, etc.

Creating the reports that sort out these needed categories in an efficient manner will require hiring a programmer to create an Excel Visual Basic program that will automatically report these and other necessary categories.

Voices for Quality Care is working with a fellow long-term care citizen advocacy, the Massachusetts Advocates for Nursing Home Reform, MANHR, to create and pay for this needed software. In order to complete this project, Voices will need to contribute half of the cost which we calculate will be less than \$4000.

Washington Post Story: https://www.washingtonpost.com/business/economy/opioid-overdoses-bedsore-and-broken-bones-what-happened-when-a-private-equity-firm-sought-profits-in-caring-for-society-s-most-vulnerable/2018/11/25/09089a4a-ed14-11e8-baac-2a674e91502b_story.html?noredirect=on&utm_term=.b639d19d233b

Esquire Story: <https://www.esquire.com/news-politics/politics/a25323717/carlyle-group-nursing-home-patients-care/a25323717/carlyle-group-nursing-home-patients-care/>

