



The California Long Term Care Ombudsman Association
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The Re-Authorization of the Older American Act Hearings: San Francisco

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Secretary Sibelius and Assistant Secretary of Aging Kathy Greenlee.

My name is Benson Nadell and I wish to respectfully enter the following Testimony in the Public Record, as it pertains to those sections of the Older American Act, which refer to the Long Term Care Ombudsman Program's role in Resident Rights, and Protection of Vulnerable Residents. The California Long Term Care Ombudsman Association is recommending a technical amendment to Section 712 of Title V11 of the Older American Act. I am particularly entering this testimony on behalf of the most vulnerable of the residents of nursing homes and assisted living and other residential care settings: those who are incapacitated.

The California Long Term Care Ombudsman Association represents the majority of the Local Long Term Care Ombudsman Programs in California. The following recommendations are based on the collective experience of the local programs in attempting to resolve cases of poor care, neglect, violations of residents' rights, and abuse. This testimony is in keeping with the Older American mandate that Ombudsmen make recommendations to improve the conditions of residents in long term care.

The following Testimony addresses two pathways for amending the Older American Act. CLTCOA, The California Long Term Care Ombudsman Association recommends a conservative approach designed to enhance the effectiveness of the Ombudsman Program in providing better resolutions on behalf of those residents who are "Un-Represented"

with serious cognitive deficits- stemming from Alzheimer's Disease or brain-injuries stemming from Alzheimer's Disease, or brain-injuries in such acute events like strokes.

Should the Ombudsman Role be strengthened in the Arena of Elder Rights and Elder Justice?

The primary Policy direction about which the California Long Term Care Ombudsman Association wishes to provide public comment is the enhancement of the Ombudsman role in resolving issues around **Elder Rights and Elder Justice for those most vulnerable residents in long term care- those who lack capacity and are un-represented.** In California the highest ranked reporting category-NORS category is # 66, pertains to resident-to-resident abuse. Nationally, it ranks #9, preceded by Dignity, Medications, Care-planning, and improper handling. In California these complaints turn out to be also contingent, as the investigation of each incident proceeds. In California many local Ombudsman Programs open up two cases: one for the victim, and the other for the other, abusing resident because care-planning, dignity, and staffing can be involved.

The background to these incidents is important. The acuity of nursing home residents has changed over the last 30 years, and continues to change with the type of resident admitted. Many traditional geriatric SNF have admitted younger disabled residents, often homeless, with dual diagnoses, many with serious strokes, while at the same time, there have been more admissions of the very old with moderate to severe dementia.

Un-Represented Need Ombudsman Services:

In many cases, particularly in urban areas, a high percentage of SNF residents have no family involved in their lives, and already lack capacity to consent. They are what Naomi Karp and Erica Wood Miller in an American Bar Association paper called the “*Incapacitated and Alone: Health Care Decision Making for the UnBefriended Older Person ABA 2003*) Since then the term Un Befriended” has been changed to “Un-Represented”.

The Alzheimer's Association projects a critical mass of persons with moderate to severe dementia flooding the health care system, particularly long term care.

The California Long Term Care Ombudsman Association would like to be able to advocate for these “un-befriended” or un-represented residents by being able to disclose cases to the appropriate regulatory body. The present section of the Older American Act prevents this disclosure for the sake of resolving serious cases of abuse and neglect. The Association is not recommending the abandoning of the present practice of protecting the privacy of residents who are expressing their concerns to Ombudsman. Residents have the right to this privacy and to refuse disclosure on complaint information, even when it is not in their best interests. But what about those increasing numbers without family, friend, and who lack capacity to consent? In addition, CLTCOA is not suggesting that Ombudsman function as agents in health care decisions! Nor with this this

recommendation, is the California Association of Long Term Care Ombudsman (CTLCOA) saying that such private information should be released to attorneys or those involved in litigation.

What we are saying is that Ombudsman be able to disclose on behalf of the resident who is incapacitated and lacks anyone to consent to that disclosure.

We are recommending the revision of Section 3058.(d) (2) Disclosure of complainant or resident to allow for disclosure of “unrepresented, who is unable to consent to disclosure when a failure to report may result in imminent, extreme, or life threatening harm to a resident.”

Such language should be added to the present section on Disclosure for those who are “un-represented. . . Communications between Ombudsmen and licensing agencies are confidential.

There are two legal theories or authorities that can be brought to this recommendation to modify the language on disclosure for the sake of resolving a complaint of case”

1. *The American Disability Act says that all Federal Programs should be accessible to those who are disabled. This principle of access is fundamental to the way each Ombudsman delivers services: through visitation, and private conversations without any willful interference. But then this access stops for those who are unable to give consent. What about the **Resolution part** of the Ombudsman duty? The ADA implies that even those who are un-represented by have equal access to those resolutions available to those residents who are able consent.*

2. *The second authority is the HIPAA regulations themselves. There is a section that allows covered entities to share private information of victims of abuse to law enforcement. This could be extended to Ombudsmen being permitted, at their discretion, to share private information with regulatory agencies as well as law enforcement, when there is a threshold of imminent danger of neglect or abuse.*

Nowhere in this recommendation is the California Association of Long Term Care Ombudsman (CTLCOA) saying that such private information should be released to attorneys or those involved in litigation.

Expansion of Ombudsman Services is the other policy pathway that may reflect recommendations to the Re-Authorization of the Older American Act. The rationale of this to reflect the changes from the modernization of the Long Term Care System, where the Ombudsman focuses on Transitions from nursing homes to other LTC settings, including home and community LTC services. More and more skilled nursing facilities in California are focusing on Rehabilitation, where residents are admitted from acute hospitals, for rehabilitative services or post-acute care, and then discharged to other settings. This is a different model of long term care, where a resident resides for a long duration in a nursing home, and the visiting Ombudsman establishes a relationship with the resident over time, building on that trust and rapport, to better advocate for the

resident. Now in many more SNF the admission and discharge of residents can be at 60 to 80 % each month. This puts pressure on the conventional model of providing Ombudsman services. Establishing advocacy relationships are difficult and the cases require an acceleration of work, with resolutions occurring before the resident leaves these SNF. Shall the Ombudsman follow the person?

In the AoA Summary of Ombudsman Activity, NORS (“National Ombudsman Reporting System) categories around eviction and discharge rank number 2, after call bells not being answered. In fact in Rehab skilled nursing facilities there is a shift away from staffing for “custodial care” and towards “Rehabilitation” with less focus on chronic or “custodial “care issues. Call bells don’t get answered as much. And in Rehabilitation skilled nursing facilities the chasm between post-acute care and chronic care has widened. The Older American Act must address the increase in complaints is the arena of residential care. There is no Federal Standard of care for assisted living or residential care. Not all states have a Medicaid waiver for residential care-certainly not California in any encompassing way. Over-sight is a challenge in this growing sector of the long term care system. The Ombudsman Programs are challenged in each state to both monitor these facilities through visitations and to handle cases which are referred to local Programs. With the shift to home and community based care, there is a projected increase in the utilization of residential care by residents with much higher pre-SNF acuities.

This trend of residents moving quicker through the existing long term care system, is putting pressure on assisted living facilities. This in turn has resulted in an increasing demand on Long Term Care Ombudsman services, without even expanding the mandate. With the nursing home transition efforts in various states, and the modernization of long term care services with an emphasis on home and community settings, those residents who remain in nursing homes will be less functional, with a higher co-morbidity, and greater cognitive deficits. These residents will be the clients of the Ombudsmen programs. Rather than follow residents into these community settings, it is imperative that we return to the core mission of the Long Term Care Ombudsman Program.

It is the position of the California Long Term Care Ombudsman Association, that any expansion without expansion of the Federal allocation would constitute a dilution of the Federal statutes commitment to residents on nursing homes and assisted living facilities. If there is no increase in allocation then there should be no expansion of Ombudsman services.

This Re-Authorization of the Older American Act is a momentous one. So much is changing in the delivery of long-term care services and how chronic care is managed. More Ombudsmen throughout California are focused on residential care and assisted living residents as part of the shift of residents with higher acuity to this less regulated level of care.

But we need to focus on improving the effectiveness of our core function: to identify problems, which affect health, safety, well being, and rights of residents, and work towards brokering effective resolutions.

The California Long Term Care Ombudsman Association wishes to enter this testimony to reflect the emerging policy focus on Elder Rights and Elder Justice. The Ombudsman Program must be able to resolve issues of neglect and abuse for those who are “un-represented.”