

National Consumer Voice for Quality Long-Term Care

Statement on Long-Term Services and Supports

Submitted to the 2015 White House Conference on Aging

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With growing numbers of aging persons and frail elders depending on long-term services and supports, National Consumer Voice for Quality Long-Term Care (www.theconsumervoice.org) makes the following five recommendations to complement the important statement on this critical topic for the 2015 White House Conference on Aging:

1. Person-Centered Care. It is not now and will not be sufficient to define care by its provision, but the meaning of care must be defined by a culture and commitment that puts the person receiving the care at the center of the services. This was the great promise of the Nursing Home Reform Act when it was signed into law in 1987 and should apply to all care recipients regardless of setting. The principle of person-centeredness must be owned by the public nationwide, by states, communities, institutions, healthcare professions, payers and providers. Without establishing person-centeredness in long-term care, our nation fails its aging population, particularly all those who are or will depend on others for their care and for their quality of life. Person-centeredness becomes a critical policy and program issue as services are contracted to companies that make decisions about the type and location of services that will be paid to providers on behalf of dependent persons. Person-centeredness also becomes critical as more long-term care consumers suffer from complex diseases including dementia that are challenging to caregivers.

2. Quality of Care. Care must also be defined by quality standards. Conditions in over a third of America's nursing homes that are rated on Nursing Home Compare as 1 or 2 star are intolerably poor and according to a recent report by the DHHS Office of Inspector General are dangerous as well, causing adverse events including injuries due to substandard treatment. Despite these ongoing critical care problems, nursing home enforcement actions are declining in number, and enforcement in cases of nursing home non-compliance with federal regulations - including poor care, abuse and neglect - continues to be used ineffectively, with remedies imposed not matching the severity of care problems and the full range of remedies available. In order to ensure quality care, we must fully enforce the nation's laws and regulations governing nursing homes. In addition, poor care conditions are not limited to nursing homes but are prevalent across long-term care, including assisted living programs and facilities as well as care provided in the home; the regulation and oversight of these settings must be strengthened as well to protect consumers and enhance their quality of life and quality of care. Lastly, we believe that the continued reduction of the use of physical and chemical restraints among long-term care consumers, as well as the protection of consumers' constitutional rights through the elimination of forced arbitration clauses in long-term care contracts and any other measures that make it more difficult

for consumers to seek legal remedies, is critical for the improvement of quality of life and quality of care in all long-term care settings.

3. Long-Term Care & Direct Care Workforce. Another critical component of quality long-term care is having sufficient nursing staff, having direct care workers adequately trained to address the complex health and behavioral conditions they will face, having staff compensated with a living wage and reasonable health and time-off benefits so they can remain on the job, and having staff supported in their work by administrators and supervisors who ensure that the direct care workers can focus on quality outcomes for residents and consumers. Specifically, Consumer Voice calls for 4.1 hours of direct nursing care per resident each day in nursing homes, a direct service registered nurse on duty in nursing homes around the clock and not just a single eight hour shift as current law requires, and use of objective payroll data to confirm actual staffing levels in nursing homes.

4. Assisted Living. These burgeoning services are designed to fill a vital need for people who may have only modest medical requirements but who require assistance with activities of daily living and around the clock supervision or care. Yet the reality is that without standards defining these facilities and the services they offer, there is great potential for misunderstanding and conflict about service expectations and the services actually made available. Many residents unknowingly sign contracts that limit the services they receive. Promises of pleasant and good care often do not occur. Staffing may be inconsistent or just not available. Food can be of poor quality. Medical needs may not be met, a particular problem as care needs increase over time. Overall, state regulations need to be strengthened and federal oversight needs to be established to protect residents. When residents run out of funds to pay for these services or when the facilities are no longer appropriate for their needs, there must be provisions in law addressing how they will be cared for and not just released to the streets. Finally, contract provisions also need to protect people as consumers; there needs to be full disclosure of what the prospective resident is getting into – and contracts need to be written in plain language.

5. Long-Term Care Ombudsman Program. Access to an independent advocate is critical to truly achieving the promise of quality and person-centered care for residents of nursing homes, assisted living, board and care, and similar long-term care facilities. Long-Term Care Ombudsmen resolve complaints raised by or on behalf of individual residents, empower residents to advocate for themselves, and address issues systemically to improve care and conditions for all residents. Appropriations to adequately fund the Long-Term Care Ombudsman Program are necessary to ensure that all residents have access to an ombudsman. Expansion of the program beyond nursing homes to board and care and assisted living occurred without additional resources. Long-Term Care Ombudsmen help assure that the residents' voice is heard, not only at individual facilities, but also in policy debates at the state and national levels. A growing number of states have expanded the long-term care ombudsman program to also advocate for consumers receiving care and services in community based settings. Considering that many of these consumers have needs similar to those of residents living in long-term care facilities, it is reasonable to promote their access to an independent advocate as well. Any future expansion, however, must include adequate resources to support additional capacity and achieve program effectiveness.