Dignity Alliance Massachusetts

Older Americans Act Regulations Update Comments – August 15, 2023

Regulations.gov "2023-12829"

Dignity Alliance Mass, a new advocacy coalition for older adults, people with disabilities, and their caregivers, was formed at the outset of the COVID-19 Pandemic. We greatly appreciate this opportunity provided by the Agency for Community Living to provide feedback for improving the implementation of Older American Act (OAA) programs and services, input from the aging and disability networks, and the people served by OAA programs.

It's been thirty-five (35) years since the last comprehensive review of OAA regulations. With increasing numbers of older adults, especially in the 85+ category, the regulations should be reviewed, and public input solicited following each decennial census.

By 2030 more people in the United States will be older than age sixty-five than younger than age five. America's health care system is unprepared for the complexity of caring for a heterogenous population of older adults—a problem that has been magnified by the coronavirus disease 2019 (COVID-19) pandemic. The National Academy of Medicine's Vital Directions for Health and Health Care: Priorities for 2021 initiative, identifies six vital directions to improve the care and quality of life for all older Americans.

- Create an adequately prepared workforce;
- Strengthen the role of public health;
- Remediate disparities and inequities;
- Develop, evaluate, and implement new approaches to care delivery;
- Allocate resources to achieve patient-centered care and outcomes, including palliative and end-of-life care; and
- Redesign the structure and financing of long-term services and supports.

If these priorities are addressed proactively, an infrastructure can be created that promotes better health and equitable, goal-directed care that recognizes the preferences and needs of older adults. Just as programs and services for older adults have been developed since 1965 to meet the changing needs of older adults and people with disabilities, these needs should be re-evaluated at reasonable intervals across successive national administrations. **We respectfully submit the following comments and suggestions:**

Support Definition Including Friends and Neighbors within the meaning of "family caregiver "(Title III)

The Older Americans Act recognizes the significant benefits of involving families in care-giving to help older adults remain as independent as possible whether in an institutional model or home and community-based model. However, there are many older Americans who do not have a family support network or, at least, one that is close to where they live. This includes widowed older adults, older adults who may be estranged from their families, and older adults who did not have a spouse or children. Over the past seven decades, America has gone through a historic transformation in household living arrangements with a record proportion of adults, now one in seven, living alone, amounting to more than one-quarter of all U.S. households.[1] **(1321.9 (c)(1)**

Expedite and Enhance Efforts to Allow Older Adults to Return to Home and Community-Based Living. (Title III)

We recommend that grant programs be developed to improve the transitions of care from acute care hospitals to home and community-based programs and services rather than to skilled nursing facilities.[2] Too often those responsible for transition of patients from acute care to post-acute care resort to recommending patients go to a skilled nursing facility.[3] Financial support for both hospitals and home-care organizations, including independent living centers and aging access points is needed to develop or expand programs such as "Why Not Home," or "Home Instead."[4], [5], [6]

Poorly managed care transitions can lead to diminished health and increased cost. Inadequate care coordination, including inadequate care transitions, was responsible for $25 - $45 billion of wasteful spending in 2011 through avoidable complications and increased hospital re-admissions. As health care costs have increased, that wasteful spending is undoubtedly more today.

Ordinarily. The discharge process is managed without review, but it should be carried out as a decision made by the client/patient or designated Guardian, or with a family member or other designated person who might, under normal circumstances, be returning the client home. In medical and human rights terms, a discharge decision should be one requiring Informed Consent by the patient/client, and not be a bureaucratic step executed by a hospital employee, without review by anyone. Yes, nurses often do this in some cases.

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[1] Living alone in America | The Hill
[2] In Post-Acute Care, Many Prefer to Go Home (managedhealthcareexecutive.com)
[3] From facility to home: How healthcare could shift by 2025 | McKinsey
[4] New Data Shows Most Americans Prefer Care in Home (homeinstead.com)
[5] Your Next Hospital Bed Might Be at Home - The New York Times (nytimes.com)
[6] 'Why Not Home?' Program Improves Efficiency of Care Transitions (reliasmedia.com)

Authentic Informed Consent would require the presentation of alternatives, which should include the option of returning to home and community-based care, as well as the option of Rehabilitation, or Independent Living or Nursing Home Care if required and if selected by the patient/client. Dignity Alliance submits and proposes that the Discharge procedure be elevated to one requiring both a witness and a signed consent form that affirms and includes the patient/client's participation, preference, and agency in that decision. This text should not be read as mandating a specific solution.

It needs to be widely understood by patients, family members, and advocates, that whenever a physician, or sometimes a social worker, or a nurse recommends institutional care it does not mean a patient/client is under any obligation to comply with that recommendation. Just like taking a drug or an injection, the patient/client has every right to refuse, if they so desire.

As it turns out, the way our institutional care system is presently arranged, once a person is admitted to hospital and becomes a patient, the decisions made by the Primary Care physician in community can be, and often are, overruled by the attending physician in the hospital, whether it is prescription drugs like a strong tranquilizer or even the ability to walk around. And, once in the nursing home, medical care is again transferred to a third physician employed by the nursing home. The point was, and is, a hospital-based physician's judgment about the patients capacity ought not be allowed to trump the judgment of a primary care physician who knows the patient/client over a much more extended period of time, and has long since made the judgment that institutional care or strong tranquilizers are not needed on a daily basis.

Training Program for AmeriCorps Long-Term Surveyors (Title VII)

One of the most significant failures of America's Long-Term Care system is the lack of oversight of providers – skilled nursing facilities (nursing homes) and home care programs. States are, for the most part, unable to find enough trained surveyors to respond to nursing home and home care complaints.

Evaluating state performance during Fiscal Years **2015-2018** for the 12 (of 19) performance measures that focused solely on nursing facilities, the HHS Office of Inspector General (OIG) finds widespread noncompliance by states with federal requirements for nursing home surveys and limited oversight and enforcement by CMS.[7]

Surveyors are tasked with investigating fraud, waste, and neglect and promoting person-centered quality care. More staff are needed to successfully protect older Americans and people with disabilities who are needed.

Utilizing the **AmeriCorps Seniors Program**,[8] or a comparable program, volunteers would be trained through pilot programs to serve as deputies for state surveyors with the same unfettered access and authority to issue citations for deficiencies. **(1324.11 (e) (3) (iv)**

[7] Nursing Homes | HHS-OIG

[8] AmeriCorps Seniors | AmeriCorps

Suicide Prevention Among Older Americans[9] (Title VII)

Suicides among older Americans is increasing[10] and, despite the introduction of the 988 help line, too many older adults are unaware of this vital program.[11] An article in *PSYCHOLOGY TODAY* reported: "Statistics from the National Council on Aging state that those 85 years and older have the highest suicide rate of any age group. It is over four times higher than the nation's overall rate of suicide[. As with most age groups, the majority of elders who kill themselves are male. As high as those figures are, the American Association for Marriage and Family Therapy (AAMFT) suggests that the rates for elder suicide are under-reported by 40 percent or more due to what they refer to as "silent suicides." These would include overdoses, self-imposed starvation, and dehydration, as well as accidents. The rate of suicide completion in this age group is also high due to the lethality of methods used."

ABC News recently reported (August 10, 2023),[12] "A total of 49,449 Americans died by suicide in 2022, the Centers for Disease Control and Prevention said Thursday.

This is a 2.6% increase from 48,183 in 2021 and the highest number ever recorded, according to provisional numbers released in a new report from the federal health agency.

The greatest increase was seen among adults aged 65 and older, which was up 8.1% from 2021, and the second highest increase was in those aged 45 to 64, with a 6.6% rise. There also was an increase among those aged 25 to 44, but of just 0.7%

The CDC said suicides have been increasing almost every year since 2006 -- with exceptions in 2019 and 2020 -- and that immediate action will need to be taken to address this crisis.

"The troubling increase in suicides requires immediate action across our society to address the staggering loss of life from tragedies that are preventable," Dr. Debra Houry, the CDC's chief medical officer, said in a press release. "Everyone can play a role in efforts to save lives and reverse the rise in suicide deaths." Therefore, programs to prevent suicide among older adults and people with disabilities should be among the policy tools to reduce elder abuse.

"Hoarding disorder (DSM-5) and hoarding behaviors/tendencies are increasingly becoming a public health issue, especially for older Americans. It is a mental health condition that results in excessive accumulation of possessions. This excessive accumulation and heavy content in a home cause a multitude of health risks that affect not just a resident, but sometimes, neighbors as well. 25% of fire deaths are related to hoarding. Tripping and falling hazards, respiratory problems, and infestations are a few of the physical risks to an older American's health. Additionally, there

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[9] https://www.forbes.com/sites/anafaguy/2023/08/10/suicide-rate-reaches-all-time-high-in-2022-cdc-data-suggests/?utm_source=newsletter&utm_medium=email&utm_campaign=dailydozen&cdlcid=63d81036c4fa70c7258bf807&section=breaking&sh=471755c658b8

[10] Understanding and Preventing Suicide in Older Adults (ncoa.org)

[11] Why Do the Elderly Commit Suicide? | Psychology Today

[12] https://abcnews.go.com/Health/50000-americans-died-suicide-2022-record-high-number/story?id=102170665

are psychological and social hardships that result. Older Americans who hoard are at a greater risk for isolation from community."[13]

Funding is needed to ensure mental health care, peer support programs, and in-home help for older Americans impacted by behavioral health conditions. It is when people are in their older years that we see the most severe conditions and the most dire need for help. Please take note of this need and help us to address it going forward"**(1324.201)**

Supported Decision-Making[14] (Title VII)

We support efforts to allow more self-control through the encouragement of supported decision-making. The law has traditionally responded to cognitive disability by authorizing surrogate decision-makers to make decisions on behalf of disabled individuals. However, supported decision-making, an alternative paradigm for addressing cognitive disability, is rapidly gaining political support. According to its proponents, supported decision-making empowers individuals with cognitive challenges by ensuring that they are the ultimate decision-maker but are provided support from one or more others, giving them the assistance needed to make decisions for themselves.

(1321.93)

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[13] How Family and Friends Can Support a Person with Hoarding Disorder - Virtual Workshop on March 23 - Old Colony Elder Services (ocesma.org)
[14] Supported Decision Making - Self-Determination (ku.edu)