



April 12, 2024

The Honorable Bob Casey
Chairman
Senate Special Committee on Aging
Washington, DC 20510

The Honorable Mike Braun
Ranking Member
Senate Special Committee on Aging
Washington, DC 20510

Submitted Electronically: HoardingDisorder@aging.senate.gov

Dear Chairman Casey, Ranking Member Braun, and Members of the Special Committee on Aging:

LeadingAge and our members are grateful for the committee's focus on older adults and attention to hoarding as a contributing factor in our members' abilities to continue to serve their communities and fulfill their missions.

We represent more than 5,400 nonprofit and mission-driven aging services providers and other organizations that touch millions of lives every day. Alongside our members and 36 partners in 41 states, we use applied research, advocacy, education, and community-building to make America a better place to grow old. Our membership encompasses the continuum of services for people as they age, including those with disabilities. We bring together the most inventive minds in the field to lead and innovate solutions that support older adults wherever they call home.

In solicitation of feedback from our members, their collective voice echoed that hoarding disorder is a significant mental health concern that endangers their communities. Hoarding disorder in a single resident effects all other residents across their community or building and the effect on the individual that hoards is comprehensively negative. There are direct deleterious correlations to the individual's socialization, health, mobility, community engagement, wellbeing, among others.

Because of the stigma and embarrassment associated with hoarding, families and friends no longer visit residents creating further isolation and perpetuating the seeking behaviors attributable to accumulation of belongings and hoarding. Members also referenced stigma and embarrassment as contributory factors limiting resident willingness to address their behaviors. Because of the underlying mental health drivers that manifest as hoarding behaviors, language and approach when offering services is important to build trust with the resident and encourage change. The sensitive nature of mental health adds layers of complexity to the physical limitations associated with an overly cluttered or filthy living space.

Eviction of older adults from our mission driven members for failure to maintain livable conditions within their units is in direct conflict with our members' missions.

As mission driven providers of senior services our members strive to serve their communities through service and connection to housing. When individuals with hoarding disorder are unable or unwilling to address the underlying conditions causing their dangerous hoarding behaviors, some individuals leave their landlords no option but to terminate their leases. For low income and affordable senior housing providers- that means offering deeply subsidized housing units to older adults with limited incomes. When hoarding leads to unsafe living conditions or filth that effects the broader community, members can be forced to terminate leases forcing their tenants to the streets.

Members are in difficult positions as their missions remain committed to serving and housing older people, while their regulatory and funding streams require compliance with local building and safety codes while supporting neighbors' rights to peaceful enjoyment of their living units and spaces. Hoarding causes a unique intersection where members are forced to make difficult decisions for the benefit of their sustainability, though this occasionally leads to eviction and homelessness of some former residents.

Hoarding disorder and hoarding tendencies threaten an individual's housing stability as landlords maintain building and cleanliness standards to comply with local requirements.

Multiple members reported similar stories about residents with hoarding tendencies that led to pest infestations in their buildings. Depending upon local housing laws, one member had a resident that fell because of clutter and has been in a rehabilitation unit for three weeks. The resident is a hoarder, including hoarding of food and food waste. This has led to a fruit fly infestation that has infiltrated the entire building. Because of local housing laws, the unit is considered the property of the resident, and the housing provider is not able to go in and clean up the decaying food that has caused the fruit flies and a significant odor. Another member spoke of a resident with which the entire community had worked to remedy their hoarding. First a call to local protective services for self-neglect, then the housing unit was condemned by the local health department, the fire department issued violations against the unit. The resident was still unable/unwilling to remedy the tendencies. In both instances, tenancy termination letters were issued, and the residents were ultimately evicted. Both of these older individuals remain unhoused.

Hoarding is recurrent, and for individuals that are willing to take steps towards cleaning up clutter, requires intensive monitoring and incremental improvements.

Our members collectively agreed that individuals with hoarding disorder will continue to collect after they've run out of space even if they've previously agreed to work on decluttering. The tendencies are durational and result in our members working towards incremental improvement and compliance. If hoarding behaviors are recognized during a unit inspection, a member may work with their service coordinator to begin to engage the resident in de-cluttering their apartment. As the process begins, the resident is usually tasked with small, achievable goals such as being able to open the door fully, being able to access the window as an emergency exit, being able to open a closet door, among others. While a resident may need to work toward all of the above goals for compliance with safety guidelines outlined in the lease, our members have recognized that small steps each week over a period of time lead to higher levels of success and de-cluttering.

Similarly, members discussed how resident engagement in developing a schedule of item removal, regular cleaning, and goal-oriented decluttering such as being able to access the window, support residents' emotional reactions to their belongings and tendencies. This approach requires extensive staff training and extraordinary amounts of time day after day to see results. Consistent schedules of monitoring promote resident success to catch cluttering before it overruns a unit.

Tenant safety is the primary concern for members when residents exhibit excessive collection and hoarding.

Maintenance of a unit that is accessible both to the resident and to emergency responders is a primary focus for members providing affordable housing. For residents with hoarding disorder, keeping a unit orderly enough to access all necessary areas of a unit such as the shower, emergency exit, or even the primary door can be problematic. Belongings crowd floor space making small paths, which may become obstructed, causing fall hazards. Should this occur, emergency responders are tasked with attempting to move a gurney into a unit where the door may not fully open because of stacks of belongings. In an apartment with narrow paths for navigation, first responders can't safely access a person that has fallen. In these instances, a person's health and well-being become a significant concern.

Members attempt to create explicit and binding lease rules to help them monitor their residents' unit orderliness. This allows the housing provider to set a schedule of inspections and use this schedule to support residents in maintaining their homes with levels of clutter that pose less risk to their safety. Schedules and plans of action aren't always successful but seem to offer the resident some agency in planning and understanding how decluttering is necessary.

Mental Health services are inadequate. They are not widely available nor accessible to the older adult population in affordable housing, a portion of which are non-English speaking, further thwarting accessibility. More specifically, very few areas have dedicated mental health services for the emotional and cognitive burdens that contribute to recurrent hoarding behaviors.

Mental and behavioral health services remain woefully inadequate in scope and availability, notwithstanding convoluted and disparate payer responsibilities when service providers are available. Many low-income senior housing properties have more than two thirds of their residents dually eligible for Medicare and Medicaid further complicating coordination of services and payment.

Successful programs focus on cognitive therapy coupled with active planning, de-cluttering, and deep cleaning which are intensive and therefore costly. Very few programs exist across the country, the majority of which are grant funded. Expanding evaluation of these programs that do exist to better understand success and increase attention and funding to these unique programs could lower program expenditures in other government funded programs.

For example, service coordinators in affordable housing buildings can spend extensive time working with a single resident that hoards in hopes of keeping them housed, keeping them safe, and maintaining the community's commitment to the peaceful enjoyment of others. Intensive attention of a service coordinator to one resident, necessarily means there is less availability for other residents which could lead to increased healthcare utilization if an opportunity for an early intervention is missed.

Untreated hoarding can lead to evictions that are costly to providers.

Multiple members cited legal costs for evictions ranging from \$10,000-30,000 per eviction. If affordable housing providers are spending scarce resources on legal resources in eviction cases where hoarding has caused lease violation and uninhabitable conditions requiring additional cleaning and maintenance, those funds could have been used to serve and house other individuals. The unit will also be vacant for a longer period of time before re-occupancy if significant cleaning and maintenance are necessary.

Hoarding remains a complicated challenge both for older adults and the providers that serve and house them. We appreciate the committee's interest in how hoarding is and will continue to affect the quality of life and services provided to older people. LeadingAge looks forward to ongoing collaboration with the committee in our ongoing commitment to aging services. If you have additional questions, please don't hesitate to reach out.

Sincerely,

A handwritten signature in cursive script that reads "Georgia Goodman".

Georgia Goodman
Director, Medicaid Policy
LeadingAge
ggoodman@leadingage.org