

## United States Senate

SPECIAL COMMITTEE ON AGING

WASHINGTON, DC 20510-6400

(202) 224-5364

September 17, 2024

The Honorable Xavier Becerra  
Secretary  
Department of Health and Human Services  
200 Independence Ave SW  
Washington, DC 20201

Dear Secretary Becerra:

I write today regarding a need for action to address hoarding disorder (HD) among older adults. HD disproportionately affects older adults, a population that is projected to grow significantly in coming years. As America ages, it can expect an increase in hoarding behavior, with consequences for older Americans and their families and communities. *The Consequences of Clutter*, a Majority Staff report released by the Senate Special Committee on Aging, discusses the implications of HD for an aging Nation.<sup>1</sup> The report includes information on the problems HD poses in communities across the Nation, and it provides a series of recommendations for how the federal government can respond. I urge the Department of Health and Human Services (HHS) to review *The Consequences of Clutter* and to take action to address HD in America.

HD is a chronic and progressive condition that causes a person to acquire excessive possessions that are not discarded and prevent the normal use of living spaces.<sup>2</sup> Studies suggest an estimated six percent of older adults have HD, compared to roughly two percent of the general population.<sup>3</sup> Older adults who exhibit hoarding behavior face significant consequences for their health, safety, and ability to function.<sup>4</sup> For example, excess clutter can prevent living spaces from being used as intended and give rise to problems such as falls, malnutrition, and medical complications.<sup>5</sup> Hoarding behavior also places older adults at risk of isolation, as the behavior is associated with

<sup>1</sup> See Majority Staff, Senate Special Committee on Aging, *The Consequences of Clutter: How Hoarding Disorder Affects America's Older Adults, First Responders, and Their Communities*, July 2024, (hereinafter "Aging Majority Staff Report"), [https://www.aging.senate.gov/imo/media/doc/the\\_consequences\\_of\\_clutter.pdf](https://www.aging.senate.gov/imo/media/doc/the_consequences_of_clutter.pdf).

<sup>2</sup> Randy O. Frost et al., "Excessive Acquisition in Hoarding," *Journal of Anxiety Disorders* 23, no 5, June 2009, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2735347/>; See also Randy O. Frost and Tamara L. Hartl, "A Cognitive-Behavioral Model of Compulsive Hoarding," *Behavioral Research Therapy* 34, no 4, 1996, at 341.

<sup>3</sup> Adam Postlethwaite et al., "Prevalence of Hoarding Disorder: A Systematic Review and Meta-Analysis," *Journal of Affective Disorders* 256, September 2019, at 312; David M. Roane et al., "Hoarding in the Elderly: A Critical Review of the Recent Literature," *International Psychogeriatrics* 29, no 7, 2017, at 1081.

<sup>4</sup> *Supra*, note 1, Aging Majority Staff Report, at B-023, Statement from James C. Appleby.

<sup>5</sup> Catherine R. Ayers et al., "Functional Impairment in Geriatric Hoarding Participants," *Journal of Obsessive-Compulsive and Related Disorders* 1, no 4, October 2012, at 263; Gretchen J. Diefenbach et al., "Characteristics of Hoarding in Older Adults," *American Journal of Geriatric Psychiatry* 21, no 10, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3530651/>; "Risks Caused by Hoarding," Massachusetts Executive Office of Health and Human Services, last accessed August 22, 2024, <https://www.mass.gov/info-details/risks-caused-by-hoarding>.

stigma and often reduces access to family and social services.<sup>6</sup> Further, individuals suffering from HD are more likely to be evicted, and research suggests that evictions related to HD are linked with homelessness.<sup>7</sup> Elder homelessness is already increasing significantly in the United States and is projected to continue increasing over the next ten years.<sup>8</sup> If not properly addressed, HD could exacerbate the existing homelessness crisis.

As HD harms the health and well-being of older adults, it also negatively affects local communities and first responders. Hoarding conditions can bring about a variety of public health risks, such as animal and insect infestations or the broader spread of illnesses.<sup>9</sup> Meanwhile, medical responses in cluttered households are complicated by “limited access and collapse potential” and often require specialized personnel and extra resources.<sup>10</sup> Cluttered environments are also more likely to give rise to fires, and those fires are more likely to be severe.<sup>11</sup> Responding to a fire at a cluttered household is more difficult than responding at an uncluttered household, and poses a greater danger of injury or death for first responders.<sup>12</sup>

Many states and local communities have taken steps to address HD, but resource limitations are a challenge. Some local governments have formed hoarding task forces,<sup>13</sup> which are shown to increase the sensitivity of how local agencies respond to hoarding behavior, increase the adoption of evidence-based practices, and improve education and information sharing.<sup>14</sup> Unfortunately, hoarding task forces are frequently underfunded and difficult to maintain.<sup>15</sup> Funding and resource limitations extend beyond hoarding taskforces, with community organizations and local services providers similarly reporting being unable to serve local needs.<sup>16</sup>

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<sup>6</sup> Sage Bates et al., “Buried in Stigma: Experimental Investigation of the Impact of Hoarding Depictions in Reality Television on Public Perception,” *Journal of Obsessive-Compulsive and Related Disorders* 26, July 2020, at 1-2; *Supra*, note 1, Aging Majority Staff Report, at B-040, B-069, B-072, B-092, and B-112, Statements of Jan M. Enders, Diane M. Terada, Lindsay Heckler, Ashley B. McCullough, and Sandra Swogger.

<sup>7</sup> Carolyn I. Rodriguez and Randy O. Frost, *Hoarding Disorder: A Comprehensive Clinical Guide*, Washington, DC: American Psychiatric Association Publishing, 2023, at 182.

<sup>8</sup> Dennis Culhane et al., “The Emerging Crisis of Aged Homelessness,” University of Pennsylvania, at 3, <https://aisp.upenn.edu/wp-content/uploads/2019/01/Emerging-Crisis-of-Aged-Homelessness.pdf>.

<sup>9</sup> Gina Fleury et al., “Compulsive Hoarding: Overview and Implications for Public Health Nurses,” *Journal of Community Health Nursing* 29, no 3, 2012, at 158.

<sup>10</sup> *Supra*, note 1, Aging Majority Staff Report, at B-037-B-038, Statement of Sean Patrick Carroll.

<sup>11</sup> “The Fire Safety Dangers of Having Too Much ‘Stuff’ in the Workplace and in the Home,” National Institutes of Health, last accessed August 22, 2024, <https://ors.od.nih.gov/News/Pages/The-Fire-Safety-Dangers-of-Having-Too-Much-%27Stuff%27-in-the-Workplace-and-in-the-Home.aspx>.

<sup>12</sup> “Hoarding,” National Fire Protection Association, last accessed August 22, 2024, <https://www.nfpa.org/Education-and-Research/Emergency-Response/Hoarding>; Ryan Pennington, “Tactical Considerations for Hoarding Fires,” *Firehouse*, February 15, 2021, <https://www.firehouse.com/operations-training/article/21206439/tactical-considerations-for-hoarding-fires>.

<sup>13</sup> “The Role of Hoarding Task Forces,” International OCD Foundation, last accessed August 22, 2024, <https://hoarding.iocdf.org/for-community-responders/working-with-hoarding-disorder-in-the-community/the-role-of-hoarding-task-forces/>.

<sup>14</sup> Christiana Bratiotis, “Community Hoarding Task Forces: A Comparative Case Study of Five Task Forces in the United States,” *Health and Social Care in the Community* 21, no 3, 2013, at 246.

<sup>15</sup> For example, a hoarding task force in Allegheny County, Pennsylvania, disbanded after five years while the Chicagoland Hoarding Task Force reports that it has a “shoestring budget” and relies on donations. *See Supra*, note 1, Aging Majority Staff Report, at B-048 and B-074, Statements of Allegheny County Department of Human Services and Chicagoland Hoarding Task Force.

<sup>16</sup> *Supra*, note 1, Aging Majority Staff Report, at 37.

The federal government must step up to support people with HD, their communities, and their families.

The mission of HHS “is to enhance the health and well-being of all Americans,” and, as part of that mission, HHS oversees several component agencies relevant to addressing hoarding behavior.<sup>17</sup> Some component agencies of HHS have taken actions related to HD, but the Department can and should do more. For example, the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Administration for Community Living (ACL) currently lack programs or efforts specific to HD.<sup>18</sup> Further, the Centers for Disease Control and Prevention (CDC) website includes useful information on topics facing older adults, such as preventing falls among older adults, aging in the workplace, and Alzheimer’s disease.<sup>19</sup> However, Aging Majority staff were unable to identify a webpage or resources for “hoarding disorder” on the CDC website.<sup>20</sup>

*The Consequences of Clutter* includes recommendations to improve the federal response to HD and support older adults, families, and communities struggling with the condition.<sup>21</sup> The report recommends that:

- SAMHSA and ACL should develop HD-specific training, technical assistance, and other guidance for communities and providers, including guidance for establishing and sustaining hoarding task forces.<sup>22</sup>
- CDC should promote greater public awareness of HD, including by conducting a public awareness campaign and maintaining a webpage on the condition. Online resources should include tips for family and community members on evidence-based intervention and harm reduction for someone with HD.<sup>23</sup>
- The Centers for Medicare and Medicaid Services should explore ways to expand Medicare and Medicaid coverage for evidence-based treatment and services related to HD.<sup>24</sup>
- Federal agencies, including HHS component agencies, should increase and improve tracking of the impact of hoarding behavior. Improved data collection should include better data related to when hoarding behavior plays a role in confirmed cases of self-

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<sup>17</sup> “About HHS,” HHS, last accessed September 11, 2024, <https://www.hhs.gov/about/index.html>; “HHS Agencies & Offices,” HHS, last accessed September 11, 2024, <https://www.hhs.gov/about/agencies/hhs-agencies-and-offices/index.html>.

<sup>18</sup> *Id.*, at 38-39.

<sup>19</sup> “About Older Adult Fall Prevention,” Centers for Disease Control and Prevention, last updated May 16, 2024, <https://www.cdc.gov/falls/about/index.html>; “About Productive Aging and Work,” Centers for Disease Control and Prevention, last updated March 7, 2024, <https://www.cdc.gov/niosh/aging/about/>; “Alzheimer’s Disease and Related Dementias,” Centers for Disease Control and Prevention, last updated October 26, 2020, <https://www.cdc.gov/aging/aginginfo/alzheimers.htm>.

<sup>20</sup> *Supra*, note 1, Aging Majority Staff Report, at 39-40.

<sup>21</sup> *Id.*, at 43-45.

<sup>22</sup> *Id.*, at 43.

<sup>23</sup> *Id.*, at 43, 45.

<sup>24</sup> *Id.*, at 44.

neglect for older adults, how HD affects first responders, and when HD hinders the ability of older adults to access federal programs.<sup>25</sup>

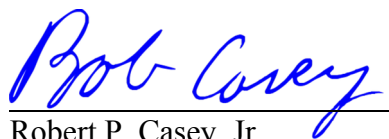
- The National Institutes of Health should continue to support research into HD, including by convening interested parties to discuss HD and older adults.<sup>26</sup>
- The federal government, including HHS and component agencies, should seek input from people with HD and their family members when considering new policies and initiatives related to the condition.<sup>27</sup>

The United States is rapidly aging, a trend that will require the federal government to attend to issues that it had not previously prioritized. Because HD disproportionately impacts older adults, families and communities throughout the United States can expect to see an uptick in hoarding behavior. The federal government must be prepared to respond.

Maureen, an 80-year-old with HD, shared the need for “more people out there willing to listen and help, making good suggestions, being positive.”<sup>28</sup> HHS can play a role in creating a positive federal response for Maureen and other older adults with HD. I look forward to working with you to establish that response. Accordingly, I ask that the Department review *The Consequences of Clutter* and identify opportunities for HHS to educate, conduct research on, and support people with HD and their communities.

I look forward to remaining updated on the Department’s work on HD, as well as any barriers to progress and necessary support from Congress. Please do not hesitate to reach out to Doug Hartman with my Aging Committee staff if you have questions.

Sincerely,



Robert P. Casey, Jr.  
United States Senator  
Chairman, Special Committee  
on Aging

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<sup>25</sup> *Id.*, at 44.

<sup>26</sup> *Id.*, at 44-45.

<sup>27</sup> *Id.*, at 45.

<sup>28</sup> *Id.*, at B-020, Statement of Maureen in Connecticut.