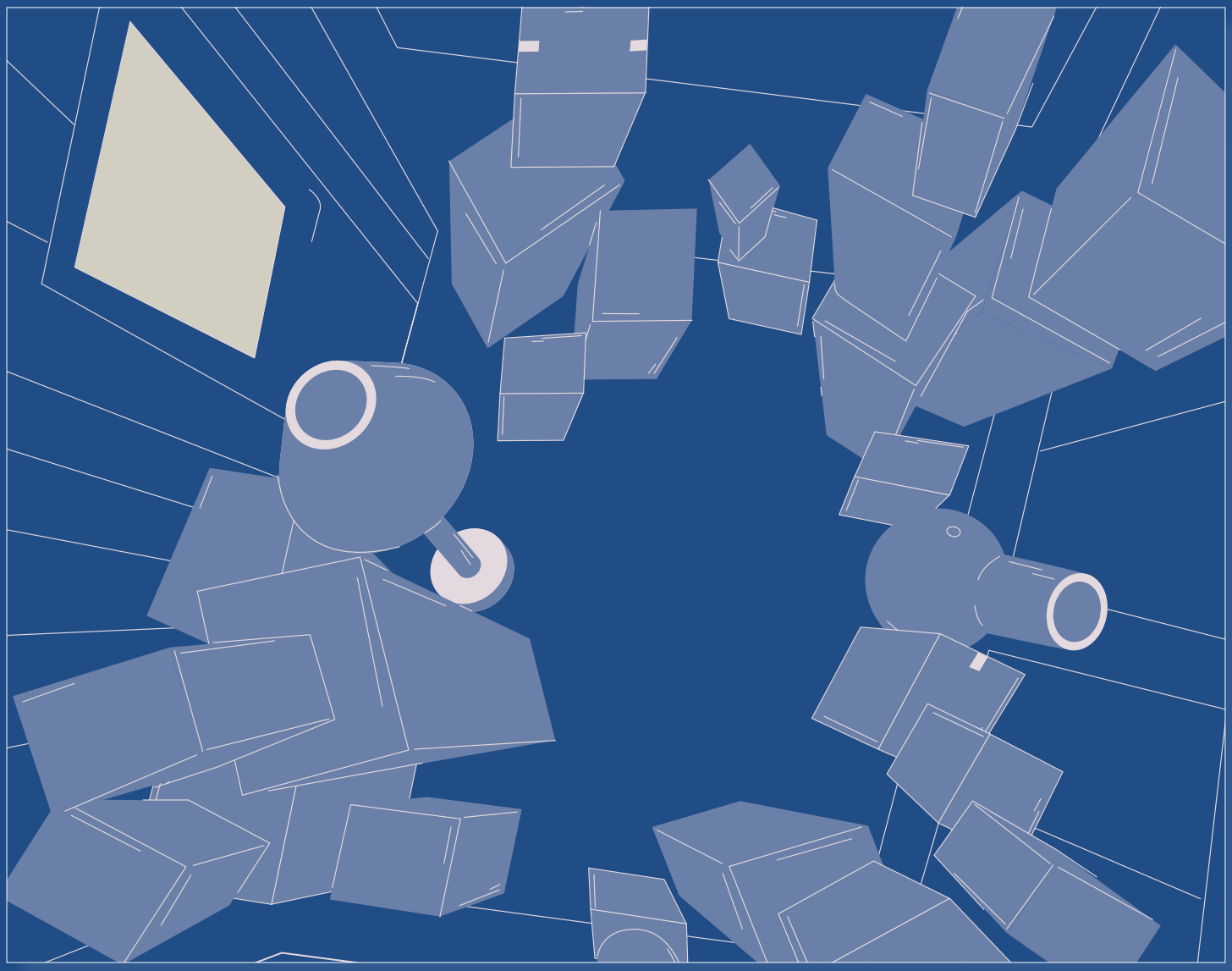
THE CONSEQUENCES OF CLUTTER

HOW HOARDING DISORDER AFFECTS AMERICA'S OLDER ADULTS, FIRST RESPONDERS, AND THEIR COMMUNITIES



A Report by the Majority Staff of

The U.S. Senate Special Committee on Aging

Chairman Bob Casey (D-PA)

July 2024

Contents

Note to Reader

The following report was developed by the Majority staff of the United States Senate Special Committee on Aging at the direction of Chairman Robert P. Casey, Jr. (D-PA). This document has been developed for informational purposes. It does not represent findings or recommendations formally adopted by the Committee.

The report includes quotes and statements from experts and stakeholders related to hoarding disorder and hoarding behavior, and the impact of hoarding behavior on local communities. Expert and stakeholder statements do not necessarily reflect an endorsement of this report nor its findings.

Introduction

Throughout her childhood and into her 30s, Deborah was neat and organized. Then, at the age of 40, she lived through an abusive relationship which changed her life, leading her to struggle with depression and anxiety. She also began to accumulate objects. For Deborah, the things she amassed filled a hole left by those in her past who had hurt her. However, they also filled up her house and cluttered her living spaces. As she grew older, Deborah's hoarding was exacerbated by sicknesses - first Lyme disease, and then mold exposure - which diminished her executive function. After turning 60, Deborah was eligible for home care, but the workers could not deal with such a cluttered environment. Deborah told them to stop trying to help her, but the rejection and the lack of care only worsened her depression, which in turn worsened the clutter in her home.[1]

Deborah is not alone.

Hoarding disorder (HD) is a chronic and progressive condition that leads people to accumulate more objects than their homes can accommodate.[2] It affects as many as 14 million people in the United States, with one estimate stating it affects around two percent of the population.[3] Hoarding prevalence and severity increases with age, affecting roughly six percent of adults over the age of 70.[4] As Americans grow older, the disproportionate prevalence of HD among older adults has national implications. The number of older adults in the United States is expected to increase from roughly 54 million in 2019 to over 94 million in 2060.[5] Because HD disproportionately impacts older adults, experts worry that aging "could fuel a rise in hoarding in the coming decades."[6]

Communities throughout the United States are already grappling with HD. An estimated one in six residents of Allegheny County, Pennsylvania, suffer from serious HD.[7] In San Francisco, up to 25,000 adults may exhibit hoarding behavior.[8] In Montana, public services

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1 *See* Appendix B, Statement from Deborah in Massachusetts, at B-003-B-005.

2 David F. Tolin and Anna Villavicencio, "Inattention, But Not OCD, Predicts the Core Features of Hoarding Disorder," *Behavioral Research and Therapy* 49, no 2, February 2011, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3038586/.

3 Ferris Jabr, "Step Inside the Real World of Compulsive Hoarders," *Scientific American,* February 25, 2013, https://www.scientificamerican.com/article/real-world-hoarding/; Adam Postlethwaite et al., "Prevalence of Hoarding Disorder: A Systematic Review and Meta-Analysis," *Journal of Affective Disorders* 256, September 2019, (hereinafter "Postlethwaite Prevalence Article"), at 312.

4 Danielle C. Cath et al., "Age-specific Prevalence of Hoarding and Obsessive Compulsive Disorder: A Population-Based Study," *American Journal of Geriatric Psychiatry* 25, no 3, March 2017, (hereinafter "Age Prevalence Article"), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5316500/.

5 Administration for Community Living, *2020 Profile of Older Americans,* May 2021, (hereinafter "2020 Older Americans Profile"), at 5, https://acl.gov/sites/default/files/aging%20and%20Disability%20In%20America/2020Profileolderamericans.final_.pdf.

6 Rose Conlon, "Hoarding May be Increasing Because of Aging Population, Scarce Mental Health Care," *NPR Morning Edition,* September 7, 2023, (hereinafter "2023 NPR Story"), https://www.npr.org/2023/09/07/1198065591/hoarding-may-be-increasing-because-of-aging-population-scarce-mental-health-care.

7 "Estimated 59,000 Allegheny County Residents Have Hoarding Problem," WPXI Channel 11 Pittsburgh, May 19, 2016, https://www.wpxi.com/news/estimated-59000-allegheny-county-residents-have-hoarding-problem/294136241/.

8 San Francisco Task Force on Compulsive Hoarding, *Beyond Overwhelmed: The Impact of Compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care,* 2009, at 1, (hereinafter "San Francisco Report"), https://www.mentalhealthsf.org/wp-content/uploads/2023/10/Task-Force-Report-FINAL.pdf.

in the Missoula area "see numerous cases of hoarding issues every month."[9]

Popular media brought attention to HD throughout the 2010s, frequently by highlighting the most extreme cases of the condition.[10] However, those media often focused on forced cleanouts as a solution, which can be simplistic and sometimes harmful. In reality, HD is a complex mental health condition that requires effective treatment, which can sometimes take years. Many people with HD will continue to struggle with clutter even after receiving treatment. That complexity speaks to the need for a national, coordinated response to HD, especially as America ages. While some relevant federal agencies have taken steps toward addressing HD, there is much more the federal government could do.

This report details the findings of a Senate Special Committee on Aging Majority staff investigation into HD and its impact on older adults. It begins with an overview of HD, including factors that give rise to the condition. It continues by examining Adult Protective Services (APS) data for trends in hoarding behavior among older adults, then explores how HD impacts the well-being of that population. This report also examines how HD challenges entire communities, including first responders and local governments, and potential treatments and responses to the condition. It also reviews the federal response to HD by examining actions taken by a selection of relevant agencies. Finally, this report includes recommendations that will help the federal government to better assist older adults and communities affected by HD.

While researching this report, Aging Majority staff collected feedback from a broad range of stakeholders, including mental health experts, social service providers, local governments, first responders, and people with HD. Written statements for the Committee were provided in response to direct outreach from Aging Majority staff, as well as a "Request for Information" disseminated through professional organizations. Stakeholder statements are cited throughout this report. A copy of the Request for Information is included in Appendix A, and a selection of stakeholder statements are included in Appendix B.

9 *See* Appendix B, Statement from Karin Fried, Organizational Consulting Services, at B-140.

10 One example is the television series *Hoarding: Buried Alive*. *See* "Hoarding: Buried Alive," TLC, last accessed June 7, 2024, https://go.tlc.com/show/hoarding-buried-alive-tlc.

Part I - What is Hoarding Disorder?

Research defines hoarding disorder (HD) as the excessive acquisition of possessions, which are not discarded, and result in clutter that prevents the normal use of living spaces.[11] HD differs from collecting, which is an organized process of acquiring objects, generally for others to admire.[12] HD typically involves little planning and is more likely than collecting to lead to excess ownership.[13] Unlike collectors, an individual with HD will typically seek to hide their objects from others.[14] HD was first recognized as an independent condition by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) in 2013.[15] However, society has recognized hoarding behaviors for thousands of years.[16]

Most people hold on to a few objects for sentimental reasons, but someone with HD has trouble recognizing when they have kept enough.[17] To someone with HD, possessions are tied to a sense of self and are "meaningful reminders of important past events" that help control an uncertain world and provide identity and belonging.[18] For example, a man collected thousands of stuffed animals because they allowed him to reclaim his lost childhood.[19] Another man collected thousands of church bulletins after his sexual orientation kept him out of the priesthood.[20] One woman was unable to part with hundreds of hat boxes because "they each have a story and a memory."[21] Another woman explained:

> I was very alienated from all of my surroundings, my wife, my family. And so what else could I do, but hold onto things when nobody else wanted them? I could bury

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11 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, (hereinafter "Frost Cognitive-Behavioral Article").

12 Carolyn I. Rodriguez and Randy O. Frost, *Hoarding Disorder: A Comprehensive Clinical Guide,* Washington, DC: American Psychiatric Association Publishing, 2023, at 9, (hereinafter "Comprehensive Clinical Guide").

13 *Id.,* at 9.

14 *Id.,* at 10.

15 Prior to 2013, hoarding behavior was classified as a type of obsessive-compulsive disorder (OCD). With time, experts realized that HD poorly fit an OCD diagnosis. *See Id.,* at 27-28. *See also* Gregory S. Chasson and Jedidiah Siev, *Advances in Psychotherapy - Evidence Based Practices, Volume 40: Hoarding Disorder,* Boston: Hogrefe Publishing, 2019, at 1 (hereinafter "Advances in Psychotherapy").

16 In 319 B.C.E., an effort to categorize human behavior included references to hoarding everyday objects. The behavior has also been depicted in literature for centuries, including *The Inferno* in the 1300s and works by Charles Dickens and Sir Arthur Conan Doyle in the 1800s. *See Supra,* note 12, Comprehensive Clinical Guide, at 3-5.

17 Scott Helman, "Where the TV Shows Get it Wrong on Hoarding; One Boston Advocate has Pioneered a Humane Approach to Treating the Problem that Other Cities are Copying," *Boston Globe,* November 1, 2016, (hereinafter "Boston Globe Treatment Article"), https://www.bostonglobe.com/magazine/2016/11/01/where-shows-get-wrong-hoarding/vnzaM9LsKM5P3HqGSrUteJ/story.html.

18 *Id.*

19 *Id.*

20 *Id.*

21 Celeste Hamilton Dennis, "'It's a Crisis': Chronic Hoarding is Costing Some Older People Their Homes," *San Francisco Chronicle,* February 3, 2024, (hereinafter "San Franciso Evictions Article"), https://www.sfchronicle.com/health/article/sf-elderly-hoarding-housing-18635623.php.

> myself in a world that was protected by the things I was familiar with.[22]

Once a person with HD begins keeping items, challenges with emotional regulation play a role in build-up and clutter. People with HD avoid distress associated with discarding objects they are attached to, while seeking positive emotions associated with old objects and acquiring new objects.[23] Problems with executive functioning - planning, memory, multitasking, and decision making - may also play a role in the condition.[24] For example, people with HD often take longer to make decisions about removing an object and suffer greater anxiety about discarding it in the "perfect" way.[25] Further, discarding requires someone with HD to examine objects that can remind them of other things they need to do, distracting them from decluttering efforts.[26] Or, a person with HD may rationalize keeping an item because they feel they will forget something important if they throw it away.[27]

Trauma and stressful events across the lifespan can impact HD, including by affecting its onset and severity.[28] Lifespan events that seem to worsen HD include interpersonal violence, having belongings taken by force, childhood break-ins, or childhood abuse.[29] Some reports suggest that the COVID-19 pandemic increased the severity of HD for people who already had the condition, with pandemic stress exacerbating already difficult conditions.[30] Additionally, biology and genetics may play a role in hoarding behavior.[31] Studies have found that between 50 to 85 percent of individuals with hoarding symptoms had family members with similar behavior.[32] Kathy, a New Yorker with HD, reported that:

> Many of us think that trauma is a big part of triggering Hoarding Disorder. I know it was for me… but I also have a family history too. It's like it was laying dormant in my brain until the multiple traumas happened then whammo.[33]

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22 Alison Caldwell, "Stacks in the Corner: One-of-a-Kind Clinic Provides Hope for Treatment of Hoarding Disorder," *UC San Diego Today,* April 30, 2020, https://today.ucsd.edu/story/stacks-in-the-corner.

23 Jasmine Taylor, "The Role of Emotion Regulation in Compulsive Hoarding," PhD thesis, Swinburne University of Technology, March 2017, at 17, https://researchbank.swinburne.edu.au/file/d48bf08d-c4dd-4d08-ae2b-239203d9037e/1/Jasmine%20Taylor%20Thesis.pdf; *Supra*, note 11, Frost Cognitive-Behavioral Article, at 347.

24 Jessica R. Grisham and Melissa M. Norberg, "Compulsive Hoarding: Current Controversies and New Directions," *Dialogues in Clinical Neuroscience* 12, no 2, 2010, at 237, https://www.tandfonline.com/doi/epdf/10.31887/DCNS.2010.12.2/jgrisham?needAccess=true.

25 *Supra,* note 15, Advances in Psychotherapy, at 14.

26 *Id.,* at 13.

27 *Id.,* at 14.

28 *Supra,* note 12, Comprehensive Clinical Guide, at 36; Catherine Chater et al., "Hoarding in the Home: A Toolkit for the Home Healthcare Provider," *Home Healthcare Nurse* 31, no 3, March 2013, https://journals.lww.com/homehealthcarenurseonline/fulltext/2013/03000/hoarding_in_the_home__a_toolkit_for_the_home.6.aspx.

29 Catherine Chater et al., "Hoarding in the Home: A Toolkit for the Home Healthcare Provider," *Home Healthcare Nurse* 31, no 3, March 2013, (hereinafter "Home Provider Toolkit"), https://journals.lww.com/homehealthcarenurseonline/fulltext/2013/03000/hoarding_in_the_home__a_toolkit_for_the_home.6.aspx.

30 Anndee Hochman, "Hoarding Increased During the Pandemic. Stress, Isolation, and Lack of Visitors Could be Why," *Philadelphia Inquirer*, November 9, 2021, https://www.inquirer.com/life/hoarding-increase-pandemic-reasons-why-help-philadelphia-20211109.html.

31 *Supra,* note 15, Advances in Psychotherapy, at 16.

32 *Supra,* note 12, Comprehensive Clinical Guide, at 109.

33 *See* Appendix B, Statement from Kathy in New York, at B-010.

Roughly two-thirds of people with HD report at least one chronic and severe medical condition and at least one other psychiatric condition.[34] Most frequently, HD is associated with major depressive disorder, which does not appear to cause HD, but does increase the severity of HD and impact treatment.[35] Among older adults, common medical conditions reported with HD include arthritic conditions, sleep apnea, head injuries, and diabetes.[36] It is unknown if HD is a risk factor for such medical conditions or if the conditions make it more difficult to declutter.[37] Some stakeholders reported that mental health conditions other than HD, as well as physical conditions or disabilities, do play a role when older adults cannot declutter their homes.[38] Gia, a Texan with HD, told Aging Majority staff:

> In 2000, I developed relapsing-remitting multiple sclerosis. This condition reduces my physical strength and stamina, making it very difficult for me to lift, carry, and sort the possessions I have hoarded. Relapses render me essentially bedbound. However, the most significant factor complicating my recovery from Hoarding Disorder is that I was born legally blind. Having low usable vision only in one eye means that when I look at a pile of hoarded items, it looks two dimensional to me; I am unable to visually distinguish the individual items. My limited vision causes me to underestimate how much stuff I actually have.[39]

34 James O. E. Pittman et al., "Implementation and Evaluation of a Community-based Treatment for Late-life Hoarding," *International Psychogeriatrics* 33, no 9, September 2021, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7483985/; David F. Tolin et al., "The Economic and Social Burden of Compulsive Hoarding," *Psychiatry Research* 160, no 2, August 15, 2008, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3018686/.

35 *Supra,* note 12, Comprehensive Clinical Guide, at 38.

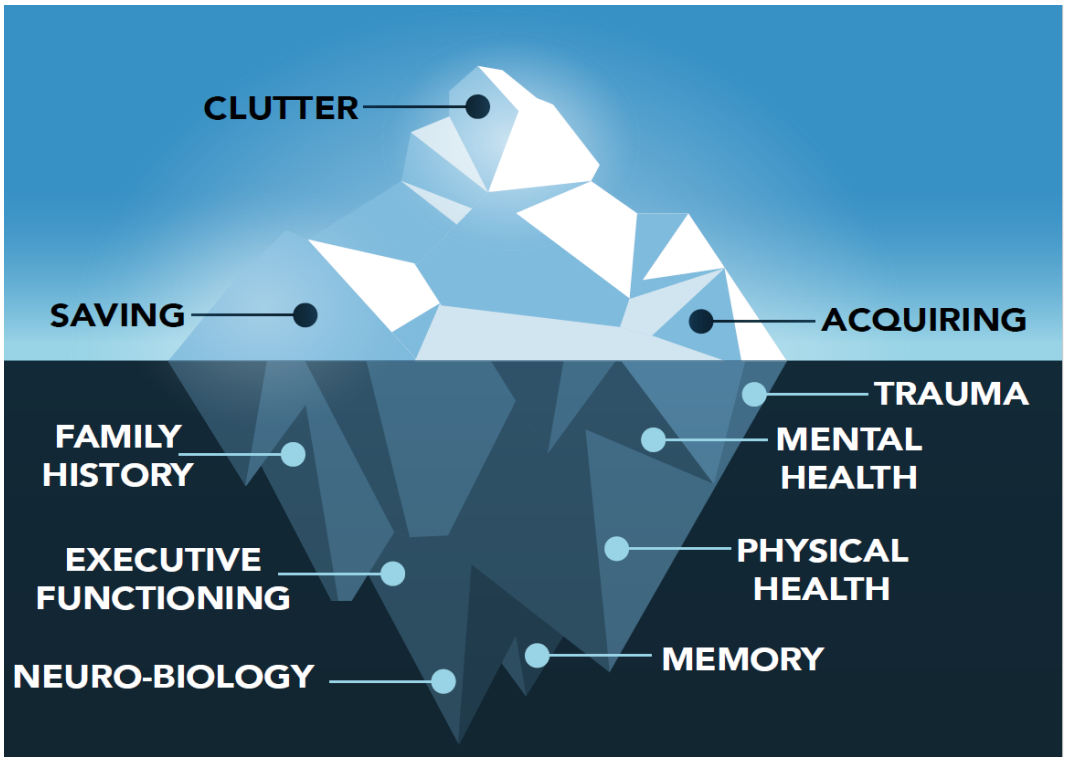
36 Catherine R. Ayers et al., "Medical Conditions in Geriatric Hoarding Disorder Patients," *Aging & Mental Health* 18, no 2, 2014, at 149-150.

37 David M. Roane et al., "Hoarding in the Elderly: A Critical Review of the Recent Literature," *International Psychogeriatrics* 29, no 7, 2017, (hereinafter "Roane Literature Review"), at 1081.

38 *See* Appendix B, Statement from Bucks County Commission, at B-062, (hereinafter "Bucks County Statement"); Appendix B, Statement from Allegheny County Department of Human Services, at B-043, (hereinafter "Allegheny DHS Statement").

39 *See* Appendix B, Statement from Gia in Texas, at B-006.

Figure 1: The Hidden Parts of Hoarding Disorder



This graphic illustrates the hidden parts of HD, which are the underwater portions of the iceberg. The hidden parts of HD include the condition's associated trauma and mental health struggles.

Source: Appendix B, Statement from Kathy in New York, at B-015.

People with HD often struggle to recognize that their condition is a problem.[40] This can make it difficult to help them. A social worker who interacts with people who hoard animals noted "intense emotional attachments" that keep those individuals from seeking help.[41] A social services provider discussed "consumers that do not understand their circumstances or what hoarding disorder is or why it is an issue due to lack of insight."[42] One person with HD stressed that the condition is "a genuine challenge" and that someone with HD "may be as baffled by it as you are."[43]

Someone with HD may clutter a rented living space to the point where they are at risk of eviction. Because HD is a recognized disability, people with HD are entitled to protections

40 *Supra,* note 15, Advances in Psychotherapy, at 2.
41 *See* Appendix B, Statement from Courtney Bearns, at B-145.
42 *See* Appendix B, Statement from Old Colony Elder Services, at B-115, (hereinafter "Old Colony Statement").
43 *See* Appendix B, Statement from Sally in Connecticut, at B-022.

under the federal Fair Housing Act.[44] Specifically, the Fair Housing Act requires landlords to provide reasonable accommodation, including by giving the resident enough time to declutter the home.[45] Yet, legal interventions often underemphasize mental health treatment, even though allowing treatment could serve as a reasonable accommodation.[46] In some cases, the need to accommodate "invisible disabilities," like a mental health condition, is more difficult to recognize than the need to accommodate physical disabilities.[47] In other cases, a reasonable accommodation can be difficult to carry out with available resources.[48] Evictions related to HD are discussed further in Part III of this report.

Hoarding behaviors can manifest in other mental health disorders, including obsessive-compulsive disorder, schizophrenia, and depression.[49] A diagnosis of HD requires that the hoarding behavior is not caused by a medical condition, including a different mental health disorder.[50] While this report generally focuses on HD, Aging Majority staff recognize that there are a range of hoarding behaviors with a variety of causes. The report's recommendations, in some cases, may also help communities address hoarding behavior that is not tied directly to HD.

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44 Lauren Brasil, "Issue Spotlight: Hoarding and Fair Housing," *Fair Housing Project Newsletter,* February 21, 2019, (hereinafter "Fair Housing Spotlight"), https://www.fairhousingnc.org/newsletter/issue-spotlight-hoarding-and-fair-housing/.

45 Kaya Laterman, "Helping Those Who Hoard," *New York Times,* June 30, 2017, https://www.nytimes.com/2017/06/30/realestate/helping-those-who-hoard.html; *See also* Department of Housing and Urban Development, *Fair Housing for Individuals with Mental Health, Intellectual, or Developmental Disabilities: A Guide for Housing Providers,* https://www.hud.gov/sites/dfiles/FHEO/images/MD%20Fact%20Sheet%20-%20HP.pdf and 42 U.S.C. § 3604(f)(3)(B).

46 *Supra,* note 12, Comprehensive Clinical Guide, at 182-183.

47 *See* Appendix B, Statement from Massachusetts Older Adult Behavioral Health Network and Massachusetts Hoarding Resource Network, at B-106.

48 *See* Appendix B, Statement from Community Health Law Project, at B-080, (hereinafter "Community Health Law Statement").

49 Gail Steketee and Randy Frost, "Compulsive Hoarding: Current Status of the Research," *Clinical Psychology Review* 23, 2003, at 910.

50 Catherine R. Ayers et al., "Hoarding Disorder in Older Adulthood," *American Journal of Geriatric Psychiatry* 23, no 4, April 2015, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7295124/.

Part II - Hoarding Disorder and Older Adults

It is estimated that over six percent of older adults have HD, compared to roughly two percent of the general population.[51]Hoarding behaviors typically emerge before the age of 20, but the severity of HD symptoms often increase with each decade of life.[52] Some researchers believe that HD symptoms worsen later in life because social cues from parents, roommates, or spouses reduce the severity of hoarding behaviors in younger people.[53] Many older adults no longer have the social connections that may have once kept in check hoarding behaviors.

The proportion of Americans who are age 65 or older is expected to increase from 16 percent of the total population in 2019 to nearly 25 percent in 2060.[54] If HD disproportionately impacts older adults, hoarding behavior will increase as well. Anecdotal evidence suggests an increase is already taking place. For example, a social worker from York County, Maine has "allotted more individual time, collaborative time and agency money" toward HD than other mental health issues.[55] Catholic Charities Hawai'i sees hoarding behavior "more frequently," including among "older adults living alone."[56] A Maryland fire captain with the Montgomery County Fire and Rescue Service noted:

> Over the last couple decades, I've seen a dramatic increase in hoarding which I believe has a lot to do with mental health and lack of mental health services. The hoarding directly impacts older people especially ones with less mobility, limiting access to parts of the house and making it extremely dangerous for the resident.[57]

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51 *Supra,* note 3, Postlethwaite Prevalence Article, at 312; *Supra,* note 37, Roane Literature Review, at 1080.

52 Linda M. Richmond, "Despite Addition to *DSM,* Few Treatments Emerge for Hoarding Disorder," *Psychiatric News,* January 31, 2022, https://psychnews.psychiatryonline.org/doi/full/10.1176/appi.pn.2022.1.18.

53 *See* Appendix B, Statement from University of Arizona College of Medicine Tucson Center on Aging, at B-151 (hereinafter "University of Arizona Statement").

54 *Supra,* note 5, 2020 Older Americans Profile, at 5; Jonathan Vespa, "The U.S. Joins Other Countries With Large Aging Populations," March 13, 2018, United States Census Bureau, (hereinafter "Census Aging Population Article"), https://www.census.gov/library/stories/2018/03/graying-america.html#.

55 *See* Appendix B, Statement from Eric Grainger, at B-148, (hereinafter "Grainger Statement").

56 *See* Appendix B, Statement from Diane M. Terada, Catholic Charities Hawai'i, at B-069, (hereinafter "Catholic Charities Hawai'i Statement").

57 *See* Appendix B, Statement from Captain Robert Ford, Montgomery County Fire and Rescue Service, at B-127, (hereinafter "Captain Ford Statement").

Inadequate Data

Although communities report anecdotal evidence of increased instances of hoarding behavior, there is little data on HD prevalence and trends. There is no national reporting system for HD, and states do not collect data in a consistent way that allows for policymakers to understand and respond to HD.

Adult Protective Services (APS) programs often encounter HD and other hoarding behavior as part of self-neglect cases, which are defined as "inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks."[58] APS data, in turn, could shed light on how hoarding behavior impacts older adults. The National Adult Maltreatment Reporting System (NAMRS) includes data on cases of adult self-neglect from throughout the United States in its annual reports.[59] Table 1 contains NAMRS data on self-neglect cases over a six-year period from fiscal year (FY) 2016 to FY 2021.

Table 1: Cases of Adult Self-Neglect, FY 2016 - FY 2021

Fiscal Year	Cases	States Reporting
2016	138,929	39
2017	142,705	41
2018	89,969[60]	31
2019	153,934	48
2020	166,135	48
2021	176,047	52

Data are from Adult Protective Services reports collected by NAMRS and included in the annual NAMRS reports: https://namrs.acl.gov/data#gsc.tab=0. Note that the number of states reporting include U.S. territories.

The NAMRS data generally show a steady uptick in self-neglect cases between FY 2016 and FY 2021. It is possible that hoarding behavior played a role in this increase. However,

58 *See* Appendix B, Statement from National Adult Protective Services Association, at B-033, (hereinafter "NAPSA Statement"); Administration for Community Living, *Adult Maltreatment Report 2020,* at 9, (hereinafter "2020 Maltreatment Report"), https://acl.gov/sites/default/files/programs/2021-10/2020_NAMRS_Report_ADA-Final_Update2.pdf.

59 "Adult Maltreatment Reports," Administration for Community Living, last modified December 1, 2023, https://namrs.acl.gov/data#gsc.tab=0; Run by the Administration for Community Living, NAMRS collects data from state adult protective services programs. *See* "National Adult Maltreatment Reporting System (NAMRS)," Administration for Community Living, last modified February 13, 2023, https://acl.gov/programs/elder-justice/national-adult-maltreatment-reporting-system-namrs.

60 The FY 2018 Adult Maltreatment Report did not provide a number for confirmed cases of adult self-neglect. Instead, the report provided a number for all reported cases of adult self-neglect and the percentage of adult self-neglect reports that were confirmed. Aging Majority staff calculated the number in the table using those data. *See* Administration for Community Living, *Adult Maltreatment Report 2018*, at 26, https://pfs2.acl.gov/strapib/assets/2018_NAMRS_Report_2024_Final_5fc5ebb229.pdf#page=33&zoom=100,0,0.

NAMRS data are an imperfect measure of the impact of hoarding behavior on older adults, because the "self-neglect" category is broad and includes behaviors other than hoarding.[61] Additionally, NAMRS is relatively new and has only published data for six years.

According to the National Adult Protective Services Association (NAPSA), many states may not collect data specifically on hoarding behaviors.[62] It is likely that data on hoarding behavior do exist in the case notes of individual APS workers, but those data are difficult to access.[63] Further, APS notes would not include data on diagnosed cases of HD, because APS workers are not typically qualified to make that diagnosis.[64]

The Pennsylvania Department of Aging was able to provide Aging Majority staff with data on confirmed cases of self-neglect due to hoarding over a three-year period.[65] Across Pennsylvania, confirmed cases increased by roughly 125 percent from FY 2020-2021 to FY 2022-2023.[66] However, it is unclear if issues related to the COVID-19 pandemic caused a change in reporting during that period.

More data across longer periods of time could allow for a better understanding of HD and an analysis of long-term trends. Even in the absence of more data, the higher prevalence of HD among older adults, combined with America's aging population, has sparked worries of an increase in hoarding due to demographics.[67] Further, it is clear that HD has consequences that impact both older adults and the communities they live in.

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61 Examples of self-neglect other than hoarding behavior include an older adult who is unable to manage their own finances, or an older adult who is unable to obtain the goods or services needed to maintain their health or safety. *See Supra,* note 58, 2020 Maltreatment Report, at 9.

62 E-mail from NAPSA to Aging Majority staff, April 30, 2024, (on file with the Committee).

63 *Id.*

64 *Id.*

65 *See* Appendix C. The Pennsylvania Department of Aging does not require the retention of APS records beyond three years, so data prior to FY 2020-2021 were unavailable.

66 *Id.*

67 *Supra*, note 6, 2023 NPR Story.

Part III - The Consequences of Hoarding Disorder for Older Adults

According to the Gerontological Society of America, older adults who exhibit hoarding behavior face "significant health, safety, and functional consequences."[68] One membership organization for non-profit service providers noted problems related "to the individual's socialization, health, mobility, community engagement, [and] wellbeing, among others."[69] Part III of this report discusses some of the consequences of clutter for older adults. Those consequences include quality of life issues, physical danger, isolation, eviction, and forced cleanouts.

Part III of this report often relies on observations from people seeking to help older adults or provide services to them. It is common for the consequences of hoarding behavior to be discovered by social service providers, first responders, or relatives entering the home.[70] For example, a social services provider in Virginia reported that home health agencies in the state often encounter cluttered environments that prevent them from helping older adults.[71] Likewise, an employee from the Mashpee, Massachusetts Board of Health shared the Board typically learns about HD "by first responders who report unsafe/unsanitary conditions within a dwelling."[72]

Quality of Life Issues and Physical Danger

For older adults with HD, indoor clutter can create quality of life issues and endanger their well-being. For example, clutter can prevent living spaces from being used as intended.[73] A study in the journal *Health & Social Work* conducted interviews with elder service providers and reported sobering details:

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68 *See* Appendix B, Statement from James C. Appleby, Gerontological Society of America, at B-023.

69 *See* Appendix B, Statement from Georgia Goodman, LeadingAge, at B-029.

70 An estimated one in six Americans provide care to someone over the age of 50, while more than half of older adults over the age of 65 are likely to require the use of long-term services and supports. Meanwhile, the federal government reports that fire and emergency medical services frequently see more older adult fall victims than fire victims. *See* AARP, *Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+*, November 2020, at 3, https://www.caregiving.org/wp-content/uploads/2021/05/AARP1340_RR_Caregiving50Plus_508.pdf; Assistant Secretary for Planning and Evaluation, *Most Older Adults Are Likely to Need and Use Long-Term Services and Supports*, January 2021, at 3, https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//199001/MostLikelyIB.pdf; Andrea Vastis, "Partnering with Fire and Emergency Medical Services to Prevent Falls," National Council on Aging, January 3, 2022, https://www.ncoa.org/article/partnering-with-fire-and-emergency-medical-services-to-prevent-falls.

71 Bennie Blackley, "Seniors: The Impact of Hoarding on Older Adults," *Alexandria Times*, November 15, 2018, https://alextimes.com/2018/11/the-impact-of-hoarding-on-older-adults/.

72 *See* Appendix B, Statement from Christine A. Willander, Mashpee Massachusetts Board of Health, at B-111.

73 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.

> Within their hoarding caseload, 80% experience substantial impairment in movement, 70% were unable to use their sofa, over half could not prepare food, 45% cold (sic) not use their refrigerator, 42% could not use [their] kitchen sink, 42% could not use their bathtubs, 20% could not use their bathroom sink, and 10% could not use their toilet.[74]

Excess clutter gives rise to a range of problems, including malnutrition and medical complications.[75] It increases the chances an older adult will lose something, including critical items such as medication or household bills.[76] One older adult with HD shared that searching for important documents is an "unbearable" agony.[77] Extreme clutter can also hinder the ability of older adults to apply for public benefits, as records are often misplaced.[78] One emergency responder from Texas discussed how, as clutter worsens, an older adult "has a smaller and smaller area to reside and remain healthy."[79]

Extreme clutter also places older adults at greater risk of falls.[80] Falls subject older adults to dangers like broken bones and head injuries and cost Medicare over $31 billion each year.[81] Elder Services of Berkshire, Massachusetts observed that, in a cluttered home, an older adult "is at risk of falling and/or is prevented from using an essential assistive device such as a walker or wheelchair."[82] The Fire & EMS Director of Nevada City, Iowa reported that his community sees "a significant number of falls in our aging population. In HD situations, those falls occur because they simply have no room to move around without tripping."[83]

Ultimately, extreme clutter can combine with age to result in a dangerous environment, even if the clutter was once manageable:

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74 *Id.,* at 263; *See also* Gail Steketee et al., "Hoarding by Elderly People," *Health and Social Work* 26, no 3, September 2001, at 180 to 181.

75 Gretchen J. Diefenbach et al., "Characteristics of Hoarding in Older Adults," *American Journal of Geriatric Psychiatry* 21, no 10, (hereinafter "Diefenbach Characteristics Article"), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3530651/; "Risks Caused by Hoarding," Massachusetts Executive Office of Health and Human Services, last accessed June 8, 2024, https://www.mass.gov/info-details/risks-caused-by-hoarding.

76 Lindsey Getz, "Hoarding - A Hazard for Older Adults," *Today's Geriatric Medicine* 13, no 1, (hereinafter "Hoarding Hazards Article"), https://www.todaysgeriatricmedicine.com/archive/JF20p10.shtml.

77 *See* Appendix B, Statement from Anonymous, at B-002.

78 *See* Appendix B, Statement from Katie Catchmark, Berks County Area Agency on Aging, at B-059.

79 *See* Appendix B, Statement from Captain William J. Crews, Garland Fire Department, at B-132 (hereinafter "Captain Crews Statement").

80 *Supra,* note 75, Diefenbach Characteristics Article.

81 *Preventing Tragedies and Promoting Safe, Accessible, and Affordable Homes, Before the Senate Special Committee on Aging, 117th* Congress, at 30, 2022, statement of Anand K. Parekh, https://www.govinfo.gov/content/pkg/CHRG-117shrg47366/pdf/CHRG-117shrg47366.pdf.

82 *See* Appendix B, Statement from Elder Services of Berkshire County, Inc., at B-090.

83 *See* Appendix B, Statement from Raymond A. Reynolds, Director of Fire & EMS, Nevada City, Iowa, at B-131 (hereinafter "Director Reynolds Statement").

> The trouble with older adults is that the hoarding disorder is exacerbated by issues relating to their age, such as changes in vision, a decline in their energy level, or even the onset of chronic health problems. Whereas they were once able to still function with their hoarding tendencies, their age has now made it increasingly hazardous to their well-being.[84]

Stigma and Social Isolation

Nearly one-fourth of adults age 65 and older are socially isolated, a condition that heightens their risk for numerous health problems.[85] Unfortunately, HD can play a role in isolating people from their families and communities. Pennsylvania's Columbia/Montour Aging Office reported clients with HD who are "generally socially isolated and often ostracized by the local community if the condition of the home is bad enough for others to know what is going on."[86] Meanwhile, a behavioral health specialist with Oregon's Rogue Valley Council of Governments discussed an older adult with HD who "is lonely and socially isolated, as she cannot have people over at her house to visit."[87]

A 2020 study found that HD is associated with a similar level of stigma as serious mental illness - and a greater level of blame.[88] Another study found that people with HD were ostracized by friends and family members to an extent similar to people with schizophrenia.[89] Stigma may cause older adults to turn down help out of embarrassment, and service providers are sometimes unwilling to enter the older adults' homes.[90] This obstructs delivery of a range of services, even though older adults with HD often suffer from multiple problems requiring assistance.[91] Sound Generations, a Seattle, Washington non-profit that provides services to older adults, noted:

> The clients miss out on delivered meals, transportation, and other services as staff cannot safely access the home or the clients cannot get out of their homes. Separate from our services, we find a number of clients are unable to receive in-home Medicaid services because of the conditions of their homes. Often, Adult Protective Services are involved, but they have limited resources to connect people to support services.[92]

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84 *Supra*, note 76, Hoarding Hazards Article.

85 "Loneliness and Social Isolation Linked to Serious Health Conditions," Centers for Disease Control and Prevention, last updated April 29, 2021, https://www.cdc.gov/aging/publications/features/lonely-older-adults.html.

86 *See* Appendix B, Statement from Columbia/Montour Aging Office, Inc., at B-076.

87 *See* Statement from Ellen Denninger, Rogue Valley Council of Governments, at B-149.

88 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, (hereinafter "Bates Stigma Article").

89 David F. Tolin et al., "Family Burden of Compulsive Hoarding: Results of an Internet Survey," *Behaviour Research and Therapy* 46, no 3, March 2008, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3018822/.

90 *See* Appendix B, Statement from Ashley McCullough, Franklin County, Pennsylvania, at B-092; Appendix B, Statement from Jan M. Enders, Area Agency on Aging for the Heart of Texas, at B-040, (hereinafter "Heart of Texas Statement"); Appendix B, Statement from Lindsay Heckler, Center for Elder Law & Justice, at B-072 (hereinafter "Elder Law & Justice Statement").

91 *See* Appendix B, Statement from Emily Bremer-Thomas, Loudoun County, Virginia, at B-104.

92 *See* Appendix B, Statement from Jams Stuivenga, Sound Generations, at B-122-B-123.

HD also presents a barrier to help from family caregivers. The International OCD Foundation notes that older adults with HD often have a strained relationship with their adult children.[93] Sometimes strained relationships result from disagreements over how hoarding behavior should be addressed, or adult children may experience anger over cluttered conditions they lived in when they were younger.[94] This can make family members reluctant to assist with an older adult's personal care needs.[95] Feelings of shame may also cause older adults to resist efforts to involve family members in their care.[96]

Perhaps unsurprisingly, a 2023 study found that people with HD appear to have higher levels of loneliness than people without HD.[97] The San Francisco Task Force on Compulsive Hoarding published the story of Ana, an older adult with the condition:

> My [grown] children constantly feel the effects of my hoarding. I can never have them over, and it makes me feel horrible that I can't invite my children into my own home. … I have no personal friends, just ones from the support groups. I am embarrassed by the chaos of my apartment and I do not allow people to come over. People think I am weird that I never allow them into my house and it strains relationships. I feel like I am a cheater in my relationships and I feel like I am missing something. I am very hard on myself.[98]

Jess from Pennsylvania shared a similar story with Aging Majority staff:

> I am too embarrassed to have people come and visit me. When I visit people, their space does not look like mine. I am clean, I am neat. But I just have this extra tension, anxiety, and overwhelming stuff that I need to go through. I want to befriend this woman I met recently, and she wants to come over. I don't know what to do! I always go to people's homes, so people don't know what my home looks like. I want her to come over, I want to swallow my pride. But it is very difficult, and I most likely will meet her outside, if I meet her. So I lack friendships.[99]

Popular media has likely played a role in increasing stigma and isolation for people with HD. Television shows have exploited the most extreme cases of hoarding and generate disdain and blame for people who experience the condition.[100] A *Salon* piece noted of the television show *Hoarders*:

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93 "How HD Affects Families," International OCD Foundation, last accessed June 9, 2024, https://hoarding.iocdf.org/for-families/how-hd-affects-families/.

94 *Id.*

95 *See* Appendix B, Statement from Sandra Swogger, Mercer County Area Agency on Aging, Inc., at B-112.

96 *Supra,* note 56, Catholic Charities Hawai'i Statement, at B-069.

97 Keong Yap et al., "High Levels of Loneliness in People with Hoarding Disorder," *Journal of Obsessive-Compulsive and Related Disorders* 37, 2023, https://www.sciencedirect.com/science/article/abs/pii/S2211364923000271.

98 *Supra,* note 8, San Francisco Report, at 17.

99 *See* Appendix B, Statement from Jess in Pennsylvania, at B-009.

100 *Supra,* note 88, Bates Stigma Article, at 2.

> While "Hoarders" does have trained experts who talk with the hoarders, what it doesn't show is those same experts giving viewers a way to relate to what a hoarder goes through when it comes to parting with their stuff. We may see them cry when faced with their possessions being taken away, but my impression is that we are meant to mock, at worst, and scorn, at best, their suffering. Who would ever want to keep dirty clothes or hundreds of teddy bears? We may see living examples of precisely those people, but what good is that if they're played up to look delusional?[101]

The portrayal of HD in popular media has implications for public policy. For example, a 2018 study led by a University of Chicago clinical psychologist found that stigma of the condition makes people less willing to fund programs for HD.[102] The same study found stigma makes people with HD less likely to seek treatment.[103]

Evictions and Cleanouts

Cases of HD frequently come to the attention of landlords.[104] In Pennsylvania, the Westmoreland County Area Agency on Aging noted:

> Hoarding puts individuals at risk of losing their housing if they rent and those that own are at risk of having their property condemned and face fines and court costs they cannot afford. We already have a housing crisis but it is even more difficult to secure housing for an individual with a history of hoarding.[105]

Evicting someone with HD can be complicated and expensive. Landlord data collected by the San Francisco Task Force on Compulsive Hoarding found eviction costs ranging from $2,000 to just under $100,000.[106] As noted in Part I of this report, people with HD are entitled to a reasonable accommodation under the Fair Housing Act for their mental illness. A reasonable accommodation could involve time to obtain mental health services and bring a rental unit into compliance with lease requirements.[107] However, resource limitations can hinder efforts to carry out an accommodation. New Jersey's Community Health Law Project reported:

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101 Rachel Kramer Bussel, "Stop Watching 'Hoarders': Our Lurid Reality TV Obsession with Mental Illness has Crossed a Line," *Salon,* January 23, 2016, https://www.salon.com/2016/01/23/stop_watching_hoarders_our_lurid_reality_tv_obsession_with_mental_illness_has_crossed_a_line/.

102 Gregory S. Chasson et al., "They Aren't Like Me, They are Bad, and They are to Blame: A Theoretically-informed Study of Stigma of Hoarding Disorder and Obsessive Compulsive Disorder," *Journal of Obsessive-Compulsive and Related Disorders* 16, January 2018, at 61-62.

103 *Id.,* at 62.

104 *Supra,* note 12, Comprehensive Clinical Guide, at 182; *See also* Appendix B, Statement from Milene Maurin, Westmoreland County Area Agency on Aging, at B-124.

105 *See* Appendix B, Statement from Milene Maurin, Westmoreland County Area Agency on Aging, at B-124.

106 *Supra,* note 8, San Francisco Report, at 2.

107 *Supra,* note 44, Fair Housing Spotlight.

> There are virtually no agencies or organizations that offer pro bono decluttering services for people with a hoarding disability in New Jersey. There is no funding for those types of services. Additionally, for elderly people on a fixed, or low, income, they cannot afford a private cleaning service to come and clean their residence out.
>
> Also, with non-profit organizations like ours, we do not have the funds to be able to pay to clean out their residences, nor do we have therapeutic staff that can provide therapy and social work services that the client needs to successfully clean out their home and maintain it in a habitable condition.[108]

Research detailed in a clinical guide on HD suggests that evictions related to hoarding behavior are linked to homelessness.[109] In San Francisco, Legal Assistance to the Elderly estimated that roughly five percent of their pro-bono eviction work in 2022 involved hoarding behavior.[110] Elder homelessness is already increasing significantly in the United States and is projected to continue increasing over the next ten years.[111] Evictions for HD can remain on a legal record for years and restrict access to future housing options.[112] Further, evictions may result in older adults being relocated to a long-term care facility, despite most older adults' preference to age at home.[113]

Older adults faced with HD-related eviction often wait to seek help until there are few options but a rapid cleanout.[114] A rapid cleanout involves a team of cleaners who quickly discard clutter, often without allowing feedback from the person who owns the items.[115] However, experience suggests that cleanouts, when not paired with mental health treatment, are counterproductive.[116] A social worker described spending "hours, months, years trying to work with people to clean out their units with only temporary improvement."[117] Forced cleanouts, in particular, "can create strong feelings of loss, anger, or severe emotional distress," which lead a person with HD to acquire new items to

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108 *Supra,* note 48, Community Health Law Statement, at B-080.

109 *Supra,* note 12, Comprehensive Clinical Guide, at 182.

110 *Supra,* note 21, San Franciso Evictions Article.

111 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.

112 *Supra,* note 48, Community Health Law Statement, at B-079; *See also* Appendix B, Statement from Jia Min Cheng, Disability Rights California, at B-085 (hereinafter "Disability Rights California Statement"). The exact amount of time an eviction remains on a tenant screening report can vary, as some states have passed laws that expunge eviction records. However, the Consumer Financial Protection Bureau reports that an eviction can remain on a record for up to seven years. *See* Consumer Financial Protection Bureau, "How Long Can Information, Like Eviction Actions and Lawsuits, Say on my Tenant Screening Record?" last updated July 1, 2021, https://www.consumerfinance.gov/ask-cfpb/how-long-can-information-like-eviction-actions-and-lawsuits-stay-on-my-tenant-screening-record-en-2104/.

113 *Supra,* note 29, Home Provider Toolkit; Joanne Binette, "Where We Live, Where We Age: Trends in Home and Community Preferences," AARP, November 18, 2021, https://www.aarp.org/pri/topics/livable-communities/housing/2021-home-community-preferences/.

114 *Supra,* note 112, Disability Rights California Statement, at B-083.

115 "8.2 The Rapid Cleanout," Hoarding Home Solutions, last accessed June 9, 2024, https://hoardinghomesolutions.com.au/courses/hhs-demo-module/lessons/decluttering-strategies-demo/topic/8-2-rapid-cleanout-demo/.

116 *Supra,* note 17, Boston Globe Treatment Article.

117 *See* Appendix B, Statement from Suzanne Norton, Jenks Center, at B-095.

counteract the negative emotions.[118] Pennsylvania's Lackawanna County Area Agency on Aging reported:

> While we as an Area Agency on Aging can at times justify a cleaning service to resolve an immediate threat of eviction, the cleaning services that exist and are affordable are simply going to gather and discard of the collected items. This method is often refused by the individual and, when consented to, can further trauma impacting the individual.[119]

Elder Services of Merrimack Valley in Massachusetts reportedly relied on large-scale cleanups for older adults with HD and found that the older adults "began hoarding again immediately."[120] The experience also made the older adults "angry, distressed and distrustful" of anyone who tried to help later, including family and social workers.[121]

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118 "Addressing Housing Issues," International OCD Foundation, last accessed June 9, 2024, https://hoarding.iocdf.org/for-community-responders/working-with-hoarding-disorder-in-the-community/addressing-housing-issues/.

119 *See* Appendix B, Statement from Kerri Anzulewicz, Lackawanna County Area Agency on Aging, at B-102.

120 Peggy Girshman, "Massive Clean Up is No Cure for Hoarding," NPR, May 2, 2011, https://www.npr.org/sections/health-shots/2011/05/02/135919186/-big-clean-out-is-no-cure-for-hoarding.

121 *Id.*

Part IV - The Community Impact of Hoarding Disorder

HD impacts not only the health and wellbeing of older adults, but also that of entire communities. Severely cluttered homes can create health risks for neighbors, including by creating risks related to mold or infestation. Clutter also complicates emergency rescues, gives rise to fires, and allows fires to spread more rapidly. HD is a mental illness, and someone who lives in extreme clutter must be approached with compassion and understanding. However, it is important to understand the communal dangers posed by extreme clutter and HD.

Challenges to Public Health and Social Services

Hoarding conditions may bring about a variety of public health risks, ranging from animal and insect infestations to the broader spread of illnesses.[122] Pests such as mice or insects may take up residence in unkempt yards and cluttered homes.[123] Some pests are "vectors" - organisms that can transmit diseases to humans, such as Lyme disease, the West Nile virus, and hantavirus.[124] In Washington state, Housing Opportunities of Southwest Washington reported problems that range from "just a smell" to more significant insect and animal concerns.[125] Elected officials in Bucks County, Pennsylvania reported that infestations from severely cluttered households spread "to next door neighbors and beyond."[126] In 2023, public health officials in Island County, Washington, warned locals about a parasitic outbreak on property where animals were hoarded.[127] People who adopted animals from the property, visited the property, or purchased items from a yard sale, were warned to monitor for symptoms related to infection.[128]

One additional challenge created by HD's generation of public health risks is the limited authority of state and local actors to respond to these risks. The ability of local authorities to respond to HD vary by state and community, with private property owners typically entitled to more control over their living conditions than renters.[129] Local health departments may receive complaints about HD. However, the Athens Ohio City-County

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122 Gina Fleury et al., "Compulsive Hoarding: Overview and Implications for Public Health Nurses," *Journal of Community Health Nursing 29*, no 3, 2012, at 158.

123 *Id.,* at 158.

124 *Id.,* at 158; "Vector-borne Diseases," Word Health Organization, March 2, 2020, https://www.who.int/news-room/fact-sheets/detail/vector-borne-diseases.

125 *See* Appendix B, Statement from Rebecca Poole, Housing authority of SWWA, at B-093.

126 *Supra,* note 38, Bucks County Statement, at B-062.

127 Jessie Stensland, "Site of Animal Rescue Infested with Parasites," *Whidbey News-Times,* March 24, 2023, Lexis+.

128 *Id.*

129 *Supra,* note 12, Comprehensive Clinical Guide, at 183.

Health Department stated that health notices do little, "since we are not addressing the underlying issue of mental health."[130]

Alternatively, relatives or others may ask APS to resolve health and sanitation problems related to HD. APS programs aim to safeguard the "safety, independence, and quality-of-life" of at-risk adults, including older adults.[131] Every state has an APS program that is authorized to receive reports of adult maltreatment or neglect, and hoarding behavior is often reported to APS as a form of self-neglect.[132] Yet, differences among state laws mean that APS programs operate under different definitions, eligibility requirements, and standards.[133] One analysis found that 10 states do not even include self-neglect in their elder abuse statutes.[134] An adult can also decline protective services unless it is determined the adult cannot make their own decisions.[135] Because adults can generally choose to forego APS involvement, the Cameron, Elk, and McKean Counties Area Agency on Aging in Pennsylvania noted that cases of hoarding behavior among older adults are particularly difficult to resolve:

> The difficulty is the Older Adult doesn't automatically become incapacitated at the age of 60 as folks would like to believe. Many older adults 60 and over are fully functional and cognitively intact - some still working full time jobs. [Older Adult Protective Services] does not have the ability to force individuals to "clean up."[136]

When APS can respond to HD, the cases are expensive, with one state reporting that each can cost up to $5,000.[137] Further, HD cases are frequently repeat clients "due to the challenging nature of the disorder."[138]

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130 *See* Appendix B, Statement from Athens City-County Health Department, at B-057-B-058.

131 "Fact Sheet: Adult Protective Services, What You Must Know," Keck School of Medicine of USC, last accessed June 13, 2024, at 1, (hereinafter "APS Fact Sheet"), https://eldermistreatment.usc.edu/wp-content/uploads/2023/07/APS-Fact-Sheet.pdf.

132 *Id.,* at 1; *Supra*, note 58, NAPSA Statement, at B-033.

133 *Supra*, note 131, APS Fact Sheet, at 1.

134 Stacey Jirik and Sara Sanders, "Analysis of Elder Abuse Statutes Across the United States, 2011-2012," *Journal of Gerontological Social Work* 57, no 5, 2014, at 488.

135 *Supra*, note 131, APS Fact Sheet, at 1.

136 *See* Appendix B, Statement from Barbara Paul, Office of Human Services, Inc., at B-066. Note that, as discussed previously in this report, forced cleanups are not a solution to HD and may even be harmful and counterproductive.

137 *Supra*, note 58, NAPSA Statement, at B-033.

138 *Id.*

Challenges to Emergency Responders and Fire Risk

Severe clutter also poses unique challenges for a community's first responders.

The National Fallen Firefighters Foundation noted that medical responses in cluttered households are complicated:

> Emergency medical responses in hoarding conditions takes on aspects of a technical rescue. The limited access and collapse potential require extra resources and often specialized rescue personnel to stabilize stacks of content and dilapidated structures.
>
> Accessing the patient through the small passageways created by the large amounts of debris requires the patient to be carried out by hand due to the inability to bring in the stretcher or the stair chair. This can make an injury or illness worse and puts emergency response personnel at a higher risk for injury.[139]

HD is a particular challenge to community fire departments. Cluttered environments are a fire risk, in part from personal items that are too close to cooking or heating equipment and may cause a fire.[140] Some examples include furniture, boxes, or stacks of paper.[141] Once a fire has started, the extra items in a cluttered environment provide additional fuel and can result in a more severe fire.[142] Because the fires linked to clutter tend to be more severe, neighbors can be quickly affected by "excess smoke and fire conditions" from these incidents.[143]

Figure 2 links to a video demonstrating how a fire can envelop a cluttered environment more rapidly than an uncluttered environment.[144] In the video, a "cluttered" fire achieves "flashover" - a point at which all items in the environment catch fire at the same time - at one minute and 40 seconds.[145] An "uncluttered" fire that was started at the same time barely spreads. Once a fire reaches flashover, anyone trapped in the fire is unlikely to be rescued.[146]

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139 *See* Appendix B, Statement from Sean Patrick Carroll, National Fallen Firefighters Foundation, at B-037-B-038.

140 "Hoarding and Fire Safety," U.S. Fire Administration, last updated April 1, 2023, (hereinafter "Hoarding and Fire Safety Webpage"), https://www.usfa.fema.gov/prevention/home-fires/at-risk-audiences/hoarding/.

141 "Hoarding and Fire Risk," Orange County Fire Authority, May 2020, https://www.ocfa.org/Uploads/SafetyPrograms/OCFA%20-%20Hoarding%20and%20Fire%20Risk.pdf.

142 *Supra,* note 83, Director Reynolds Statement, at B-131; "The Fire Safety Dangers of Having Too Much 'Stuff' in the Workplace and in the Home," National Institutes of Health, last accessed June 9, 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.

143 "Hoarding," National Fire Protection Association, last accessed June 9, 2024 (hereinafter "NFPA Hoarding Webpage"), https://www.nfpa.org/Education-and-Research/Emergency-Response/Hoarding.

144 The demonstration has scientific limits but is useful for comparison. *See* E-mail from Philadelphia Fire Department to Aging Majority staff, February 28, 2024, (on file with the Committee).

145 Flashover occurs because, during a fire, the heat that normally accumulates in the upper portion of a structure cannot be absorbed as fast as it is created and is forced back down. The resulting, rapid increase in heat causes everything to catch fire at once, even though different items have different burning temperatures. *See* Tom Kiurski, "Understanding Flashover," *Fire Engineering*, June 22, 2010, https://www.fireengineering.com/firefighter-training/kiurski-flashover/#gref.

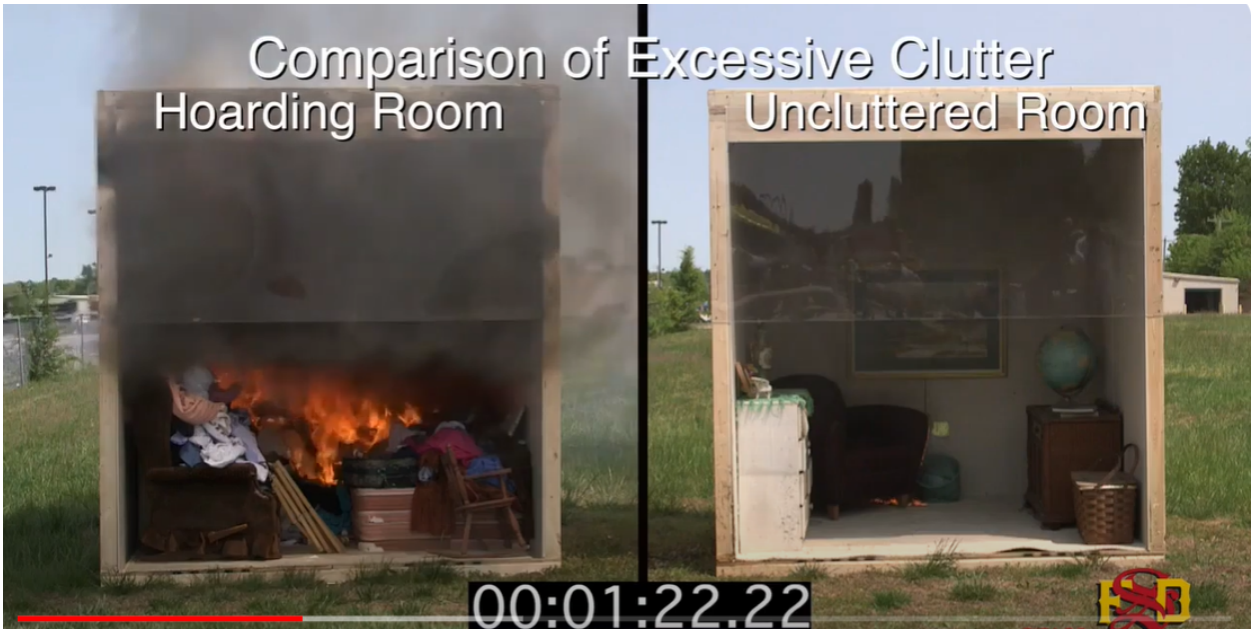
146 *Id.*

Figure 2: Link to Side-by-Side Burn

Scan the QR code with your phone, or use the following link, to view a silent video posted by the Springfield, Missouri Fire Department. In the video, two fires are lit at the same time, one in a cluttered environment and one in an uncluttered environment. The "cluttered" fire rapidly spreads and gains intensity, while the uncluttered fire barely spreads at all: https://www.youtube.com/watch?v=qy1h-vbmd78.

Figure 3: Screenshot of Side-by-Side Burn

In the Springfield, Missouri Fire Department's side-by-side comparison, a fire in a cluttered environment, left, spread much more rapidly than a fire in an uncluttered environment, right, during the same amount of time.
Image taken June 10, 2024, from https://www.youtube.com/watch?v=qy1h-vbmd78.



Data collected through the National Fire Incident Reporting System (NFIRS) show the human and financial costs of hoarding-related residential structural fires between 2014 and 2022.[147] Over nine years, 5,242 residential fires connected to cluttered environments resulted in 1,367 fire service injuries, 1,119 civilian injuries, and over $396 million in losses (see table 2).

Table 2: Loss in Hoarding-Related Residential Structure Fires per Year, 2014 to 2022

Incident Year	Incidents	Fire Service Injuries	Civilian Fire Injuries	Total Loss
2014	494	45	71	$35,344,327
2015	452	79	42	$55,991,450
2016	483	55	81	$43,860,440
2017	435	65	65	$33,754,548
2018	627	256	153	$40,191,846
2019	724	268	209	$49,141,667
2020	752	285	217	$42,194,572
2021	652	184	149	$38,447,743
2022	623	130	132	$57,159,774
Total	**5,242**	**1,367**	**1,119**	**$396,086,367**

Source: United States Fire Administration.

The NFIRS data suggest that clutter-related fires have also become more common - or, at least more widely reported. Hoarding-related residential structural fires increased over 26 percent between 2014 and 2022. Particularly notable is a single, 44 percent increase between 2017 and 2018. Reports of hoarding-related residential fires continued to increase through 2020, and then declined to a level that is still higher than 2014 (see figure 4). It is unclear if the notable increase between 2017 and 2020 was due to an actual increase in hoarding-related residential fires or a change in reporting.[148]

147 E-mail from U.S. Fire Administration to Aging Majority staff, April 19, 2024 (on file with the Committee). NFIRS is a voluntary reporting system, administered by the United States Fire Administration, that individual fire departments can use to report their activities. It contains data on roughly 70 percent of annual fire incidents. *See* "About NFIRS," U.S. Fire Administration, last updated December 13, 2022, https://www.usfa.fema.gov/nfirs/about/.

148 E-mail from U.S. Fire Administration to Aging Majority staff, April 23, 2024 (on file with the Committee).

Figure 4: Hoarding-Related Residential Structure Fires per Year, 2014 to 2022

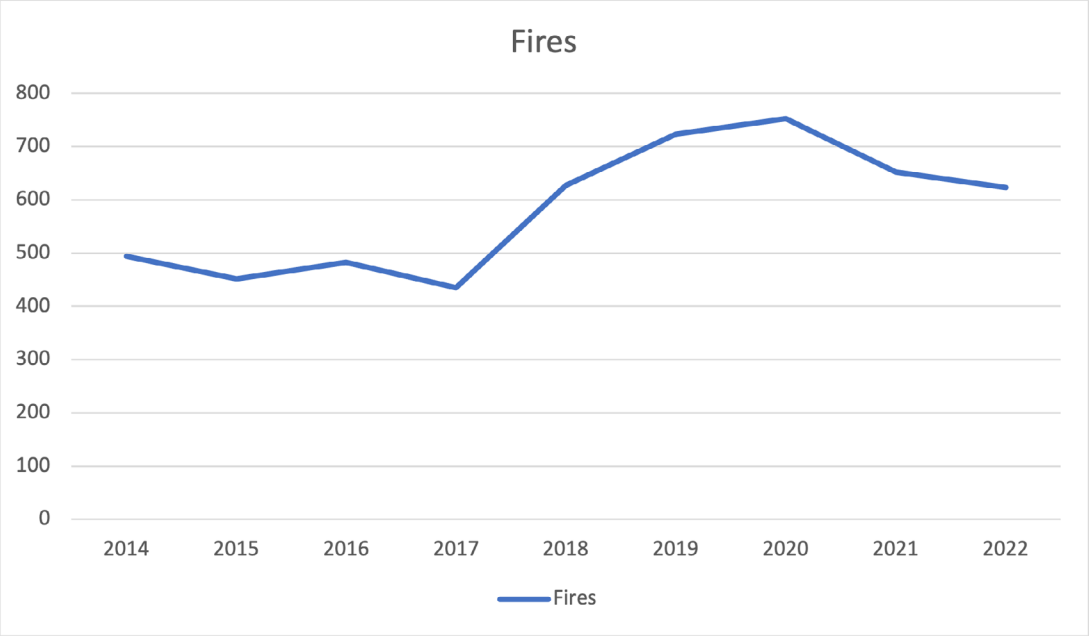


Table generated by Aging Majority staff using data provided by the United States Fire Administration.

A cluttered environment complicates fire response.[149] Within a cluttered environment, blocked windows and doors complicate entry for firefighters, piles of items make it difficult for them to move, and fires are "difficult to locate and distinguish."[150] Buildings with large stacks of items are more likely to collapse during a fire, because the stacks overload the structure even before additional weight from water is added.[151] Firefighters may also be exposed to contaminants, which can pose a risk to their health and ruin equipment. A fire captain from Montgomery County, Maryland, reported that firefighters from his department unknowingly crawled through contaminants in a cluttered home.[152] A firefighter from Milwaukee, Wisconsin likewise discussed how uniforms frequently become contaminated at cluttered homes, forcing his department to buy new ones.[153]

Ultimately, severe clutter puts firefighters at greater risk of injury and death.[154] One firefighter reported that a colleague was forced to retire after responding to a cluttered

149 Ryan Pennington, "Tactical Considerations for Hoarding Fires," *Firehouse,* February 15, 2021, (hereinafter "Tactical Considerations Article"), https://www.firehouse.com/operations-training/article/21206439/tactical-considerations-for-hoarding-fires.

150 *Id.; Supra*, note 140, Hoarding and Fire Safety Webpage; See also Appendix B, Statement of Firefighter Adam Wood, San Francisco Fire Department, at B-126, (hereinafter "Firefighter Wood Statement").

151 *Supra*, note 149, Tactical Considerations Article.

152 *Supra,* note 57, Captain Ford Statement, at B-128.

153 *See* Appendix B, Statement from Lieutenant Jeff Gauthier, Milwaukee Fire Department, at B-134.

154 *Supra,* note 143, NFPA Hoarding Webpage.

environment and "a large tub fell on top of his neck."[155] Another noted that his department has had "a number of fires where the firefighters became buried in collapsed piles."[156] A third discussed a fire that resulted in multiple firefighter injuries:

> We responded to a fire in 2022 in the Bernal Heights neighborhood of San Francisco. The front entrance of the two-story house was completely blocked by accumulated furniture and debris. Rescue crews were forced to enter through the rear, downwind side of the house. All received burns during entry. The search for possible victims was conducted by crawling over three to five feet of debris piled throughout the house, leading to multiple cases of heat exhaustion. The elderly residents were safely evacuated.[157]

Firefighters have developed special tactics to respond to an emergency in a cluttered residence.[158] For example, they may use a high-resolution thermal imaging camera (TIC) to identify the height and composition of stacks of objects.[159] Knowing a stack's height and composition helps determine whether a pile is likely to collapse on firefighters or cause a structure itself to collapse.[160] Firefighters can also use a TIC to identify objects within a home that do not move - such as bookshelves and window tops - to help maintain their orientation once inside.[161] Because clutter can prevent water from directly reaching a fire, firefighters may aim at a structure's ceiling, distributing water over the clutter and reducing fire severity.[162] Reducing fire severity creates extra time for firefighters to access the seat of a fire and extinguish it.[163]

One complication is that firefighters may not immediately know when they are responding to an extremely cluttered environment. The Buffalo, New York Fire Department suffered a line of duty death while responding to a cluttered residence.[164] From outside the residence, "there was little indication of what awaited crews as they entered."[165] The Springfield, Missouri Fire Department did not realize they were responding to a cluttered environment until a firefighter was unable to enter through a window.[166] The Department was unable to rescue one resident of the home.[167]

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155 *See* Appendix B, Statement from Firefighter Michael Wells, Prince Georges County Fire/EMS Department, at B-130.

156 *Supra,* note 79, Captain Crews Statement, at B-133.

157 *Supra,* note 150, Firefighter Wood Statement, at B-126.

158 *Supra,* note 149, Tactical Considerations Article.

159 *Id.*

160 *Id.*

161 *Id.*

162 *Id.*

163 *Id.*

164 Mike Lombardo, "Hoarders and Fire Operations," *Firehouse,* December 5, 2014, https://www.firehouse.com/home/article/10284225/hoarders-and-fire-operations.

165 *Id.*

166 Steve Pokin, "Hoarding and Squalor Often Make It Hard to Save Lives," *Springfield News-Leader*, July 5, 2014, https://www.news-leader.com/story/news/local/ozarks/2014/07/05/hoarding-squalor-often-make-hard-save-lives/12259325/.

167 *Id.; See also* "Afternoon Fire Results in Fatality," City of Springfield, October 12, 2012, https://www.springfieldmo.gov/Archive.aspx?AMID=39&Type=&ADID=.

Part V - Treating and Managing Hoarding Disorder

Although HD has only been recognized as an independent condition for a little over a decade, there are efforts to treat and manage the condition. Approaches to treatment include cognitive-behavioral therapy (CBT), peer-based workshops, and Cognitive Rehabilitation and Exposure/Sorting Therapy (CREST). Given that HD is a chronic condition, treatment takes dedicated time, effort, and works best when it is voluntary. In some cases, HD may be best managed with a harm reduction approach.

Treatment

Psychotherapy can be used to treat HD, and CBT is one of the primary treatments for the condition.[168] In CBT, a person with HD works with a mental health professional to learn how to manage beliefs and behaviors related to clutter.[169] For many patients, CBT appears to be effective at improving a range of outcomes, including "hoarding symptoms, functional impairment, and hoarding-related beliefs."[170] However, CBT appears to be less effective for HD than for other mental health conditions, such as anxiety and depression.[171] One challenge is that someone with HD will often feel unmotivated to seek treatment because they do not feel distressed about their cluttered homes.[172] Motivational interviewing therapy - an approach that "helps people resolve ambivalent feelings and insecurities" to motivate them to change their behavior - has shown promise in treating HD.[173]

Another challenge to treatment for people with HD is a lack of mental health professionals who specialize in the condition.[174] "Buried in Treasures" workshops use CBT principles but were designed as a workaround for the shortage of mental health professionals with training on HD.[175] The workshops may be led by people without clinical training - often a person who has firsthand experience with HD.[176] Advocates of Buried in Treasures suggest

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168 Kirsten Weir, "Treating People with Hoarding Disorder," *Monitor on Psychology* 51, no 3, April 1, 2020, (hereinafter "APA Treatments Article"), https://www.apa.org/monitor/2020/04/ce-corner-hoarding; "Hoarding Disorder," Mayo Clinic, last updated January 26, 2023, https://www.mayoclinic.org/diseases-conditions/hoarding-disorder/diagnosis-treatment/drc-20356062.

169 "Hoarding Disorder," Mayo Clinic, last updated January 26, 2023, https://www.mayoclinic.org/diseases-conditions/hoarding-disorder/diagnosis-treatment/drc-20356062.

170 *Supra,* note 12, Comprehensive Clinical Guide, at 143.

171 *Supra,* note 168, APA Treatments Article.

172 *Id.*

173 *Id.;* "Motivational Interviewing," *Psychology Today,* last updated June 6, 2022, https://www.psychologytoday.com/us/therapy-types/motivational-interviewing.

174 *Supra,* note 168, APA Treatments Article.

175 *Id.*

176 *Supra,* note 12, Comprehensive Clinical Guide, at 133; "The Buried in Treasures Workshop," Mutual Support Consulting, LLC, last accessed June 9, 2024, https://www.mutual-support.com/the_buried_in_treasures_workshop.

it produces outcomes similar to those seen with CBT.[177] A 2018 study in the *Journal of Psychiatric Research* found that pairing the workshops with in-home uncluttering sessions may improve outcomes further.[178]

CBT appears less effective at treating HD for older adults and may not always be the best treatment option for them.[179] CREST is an alternative method of treatment for HD.[180] CREST is modeled after cognitive rehabilitation, a group of therapies designed to "improve and restore cognitive function" for people who have experienced brain injuries.[181] CREST combines training to improve executive functioning - the ability to plan, sort, and make decisions - with exposure to distress caused by discarding objects and not acquiring new ones.[182] A study in the *Journal of Clinical Psychiatry* found a 38 percent reduction in hoarding symptoms among older adults who completed CREST, gains that did not reverse over a six-month follow up period.[183]

Harm Reduction and Chronic Management

It is often challenging to convince someone with HD to seek treatment. As noted earlier, a person with HD often struggles to recognize that their condition is a problem.[184] An expert on a National Council on Aging panel on HD and mental health in older adults noted that it is important not to force someone into treatment.[185] If a person with HD feels that they are being blamed or shamed, they may be less likely to seek help.[186] When reaching out to someone with HD, the goal should be to "plant the seed" for them to decide that they want help.[187] If someone with HD does not seek help, there still may be opportunities for family members, social workers, or first responders to work with that person to reduce the impact of the condition.

A "harm reduction" approach seeks to reduce the harm from clutter caused by HD.[188]

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177 *Supra,* note 12, Comprehensive Clinical Guide, at 143.

178 Omer Linkovski et al., "Augmenting Buried in Treasures with In-Home Uncluttering Practice: Pilot Study in Hoarding Disorder," *Journal of Psychiatric Research 107,* December 2018*,* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7437985/.

179 *Supra*, note 168, APA Treatments Article.

180 Catherine R. Ayers et al., "Cognitive Rehabilitation and Exposure/Sorting Therapy (CREST) for Hoarding Disorder in Older Adults: A Randomized Clinical Trial," *Journal of Clinical Psychiatry* 79, no 2, March-April 2018, (hereinafter "Ayers CREST Trial"), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7295125/.

181 *Supra,* note 168, APA Treatments Article; Zawn Villines, "What to Know About Cognitive Rehabilitation Therapy," *Medical News Today,* March 24, 2021, https://www.medicalnewstoday.com/articles/cognitive-rehabilitation-therapy.

182 *Supra,* note 180, Ayers CREST Trial.

183 *Id.*

184 *Supra,* note 168, APA Treatments Article.

185 National Council on Aging, "Understanding Hoarding Related to Mental Health in Older Adults," National Mental Health Awareness Day Symposium, filmed May 2, 2024, video, 59:23, at 51:26 (statement of Tamar Cooper), (hereinafter "NCA Hoarding Webinar"), https://connect.ncoa.org/products/6-understanding-hoarding-related-to-mental-health-in-older-adults#tab-product_tab_contents__1.

186 *Id.,* at 52:05.

187 *Id.,* at 52:00.

188 "How to Help a Loved One with HD," International OCD Foundation, last accessed June 9, 2024, (hereinafter "OCD Foundation Help Page"), https://hoarding.iocdf.org/for-families/how-to-help-a-loved-one-with-hd/.

Harm reduction allows a community representative or family member to focus on small changes to a person's environment that reduce risk. Examples include keeping objects away from a burner or ensuring that doors are not blocked.[189] Harm reduction may or may not motivate someone with HD to embark on more significant change.[190] However, it may improve the situation in a cluttered home.[191] Small improvements can reduce safety risks that exist for people with HD, emergency responders, and the community at large.

Ultimately, there is no "quick fix" for HD. Like other chronic conditions, such as diabetes or heart disease, HD must be managed over a lifetime. One stakeholder noted:

> There are evidence-based interventions that are proven to help people with HD to acquire less and discard more, which ultimately leads to a safer living environment, but those strategies - primarily cognitive behavioral therapy and The Buried in Treasures Workshops - are not a quick fix. A problem that has often developed over the course of decades, in secrecy, can't be resolved overnight. In fact, even when people are in recovery or have overcome their urges to save, physical clutter remains.[192]

189 Metropolitan Boston Housing Partnership, *Rethinking Hoarding Intervention,* January 2015, at 4, https://www.metrohousingboston.org/wp-content/uploads/2023/09/Hoarding-Report-2015_FINAL.pdf.

190 *Supra,* note 188, OCD Foundation Help Page.

191 *Id.*

192 *See* Appendix B, Statement from Lee Shuer, Mutual Support Counseling, LLC, at B-137.

Part VI - Community Responses to Hoarding Disorder

People with HD typically have complex needs that require a collaborative response among professionals and local agencies.[193] In responding to HD, some community actors, such as social workers, "can take roles as friendly helpers" while others, such as housing code enforcement, are more direct.[194] A response that involves professionals in both types of roles can be effective in addressing HD.[195] The Allegheny County, Pennsylvania, Department of Human Services confirmed:

> The human services system alone cannot address hoarded conditions. Addressing hoarding disorder oftentimes requires collaboration between older adult services, homelessness prevention services, services for children and families, and/or intellectual and developmental disability services, as well as the health department, animal control, local code enforcement, law enforcement and magisterial district offices.[196]

Hoarding Task Forces

Communities throughout the United States have formed hoarding task forces as a way to coordinate their response to HD.[197] Different hoarding task forces have different missions and goals.[198] The task forces typically "organize and provide public education about hoarding disorder, give out service agency information, offer trainings, and provide support to families."[199] Some hoarding task forces may work within a local government, while others are more targeted at how HD affects a certain population, such as older adults.[200] A 2012 study from a former University of Nebraska professor of social work found that hoarding task forces improve community response to HD.[201] Among the benefits are increased sensitivity in how local agencies respond to HD, greater adoption of evidence-based practices, and improved education and information sharing.[202]

Philadelphia, Pennsylvania has convened a local hoarding task force - the Philadelphia

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193 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, (hereinafter "Bratiotis Task Force Article").

194 *Id.,* at 246.

195 *Id.,* at 246.

196 *Supra,* note 38, Allegheny DHS Statement, at B-046.

197 "The Role of Hoarding Task Forces," International OCD Foundation, last accessed June 9, 2024, https://hoarding.iocdf.org/for-community-responders/working-with-hoarding-disorder-in-the-community/the-role-of-hoarding-task-forces/.

198 *Id.*

199 *Id.*

200 *Id.*

201 *Supra,* note 193, Bratiotis Task Force Article, at 249-251.

202 *Id.,* at 249-250.

Hoarding Task Force (PHTF) - which seeks to improve outcomes and reduce consequences for people with HD in Philadelphia.[203] Task force members include Jewish Family and Children's Service (JFCS) of Greater Philadelphia, the Philadelphia Fire and Police Departments, the Fair Housing Rights Center of SEPA, and the Philadelphia Corporation for Aging.[204] JFCS reported to Aging Majority staff on how the task force is helpful:

> We are able to extend our resources, discuss complex cases, refer to each other, and build relationships. The PHTF is widely known within the region's working groups and is often sought out for local counties and regions for insight into how to build a task force around hoarding disorder, needs and gaps in the community, service implementation, resource building, and more.[205]

Similar task forces exist throughout the Nation. Examples include cities such as Chicago and Boston, regions such as the greater Brockton area in Massachusetts, and entire states such as Rhode Island.[206]

203 "About Us," Philadelphia Hoarding Task Force, last accessed June 9, 2024, http://www.philadelphiahoarding.org/about.php.

204 *Id.*

205 *See* Appendix B, Statement from Jewish Family and Children's Service of Greater Philadelphia, at B-098.

206 "Hoarding Task Forces and Other Resources," International OCD Foundation, last accessed June 9, 2024, https://hoarding.iocdf.org/hoarding-task-forces/; *See also* Appendix B, Statement from Chicagoland Hoarding Task Force, at B-074-B-075, (hereinafter "Chicagoland Task Force Statement"); *Supra,* note 42, Old Colony Statement, at B-114-B-117; Appendix B, Statement from Rhode Island Hoarding Task Force, at B-118-B-121, (hereinafter "Rhode Island Task Force Statement").

Figure 5: Screenshot of the Philadelphia Hoarding Task Force Homepage

When reviewed by Aging Majority Staff, the Philadelphia Hoarding Task Force homepage provided resources on support groups for hoarding disorder, therapy for the condition, and resources for the family of people with hoarding disorder.

Image was taken on April 15, 2024, from http://www.philadelphiahoarding.org/.

Resource and Funding Limitations

While communities throughout the country have taken steps to address HD, local efforts are often underdeveloped and under resourced. A clinical guide on HD noted that "the infrastructure for community interventions is lacking," and there is a need for more trained practitioners who deliver collaborative interventions.[207]

207 *Supra,* note 12, Comprehensive Clinical Guide, at 192.

Hoarding task forces illustrate the challenges communities face in standing up a response to HD. Although task forces can provide a coordinated response, they are frequently underfunded and difficult to maintain. The Chicagoland Hoarding Task Force reported that it "operates from a shoestring budget of donations."[208] The Rhode Island Hoarding Task force has seen "an increase in request (sic) for individual case assistance," obligations that compete with their ability to support community program development.[209] In Allegheny County, Pennsylvania, a hoarding task force existed between 2012 and 2017, but ended due to leadership and funding issues.[210] A 2012 study examined five hoarding task forces and noted that "most operated without a dedicated, sustainable funding stream."[211]

Resource and funding challenges for efforts to address HD are not unique to hoarding task forces. In New York, community organizations and service providers are challenged by inadequate education and intervention tips for the condition.[212] In Arizona, a well-attended workshop on HD ended due to "lack of funding, location issues, and our individual professional obligations."[213] In Maine, an HD program helped establish three hoarding task forces, then ended after 10 years "due to lack of funding."[214] The Area Agency on Aging for the Heart of Texas reported that they do "not have the funding to address hoarding on a large scale."[215] Instead they work to rally assistance from local agencies to address hoarding behavior.[216]

208 *Supra,* note 206, Chicagoland Task Force Statement, at B-074.

209 *Supra,* note 206, Rhode Island Task Force Statement, at B-118.

210 *Supra,* note 38, Allegheny DHS Statement, at B-048; UPMC Senior Services, *Hoarding Information Review,* December 2023, at 1, (on file with the Committee).

211 *Supra,* note 193, Bratiotis Task Force Article, at 249.

212 *Supra,* note 90, Elder Law & Justice Statement, at B-072.

213 *Supra,* note 53, University of Arizona Statement, at B-153.

214 *Supra,* note 55, Grainger Statement, at B-148.

215 *Supra,* note 90, Heart of Texas Statement, at B-041.

216 *Id.,* at B-041.

Part VII - The Federal Government and Hoarding Disorder

Communities throughout the United States face challenges from HD. Many have stepped up to establish a coordinated response, despite a lack of adequate resources. Aging Majority staff examined what federal agencies are doing to study HD and assist providers, social services, families, and local communities. Some federal agencies have taken actions to address HD, although those actions are often limited in nature. Other agencies have not taken recent specific actions related to HD, even though addressing the condition and its impact would fall within their mandate.

Substance Abuse and Mental Health Services Administration

The Substance Abuse and Mental Health Services Administration (SAMHSA) "leads public health efforts to advance the behavioral health of the nation."[217] SAMHSA's 2023-2026 strategic plan does mention efforts to expand services to older adults.[218] However, a search by Aging Majority staff found no mention of the word "hoard" within the strategic plan.[219]

SAMHSA informed Aging Majority staff that the agency does not have programs specific to HD, but that it has addressed the condition through recent webinars:[220]

- SAMHSA's E4 Center of Excellence for Behavioral Health Disparities in Aging held a webinar on the condition on March 1, 2023;[221]
- SAMHSA conducted a July 28, 2023, SMI Advisor webinar on HD;[222]
- SAMHSA cosponsored a May 2, 2024 symposium on older adult mental health that included a session on HD;[223] and
- SAMHSA sponsored a June 5, 2024 webinar on HD and homelessness.[224]

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217 "About Us," SAMHSA, last updated February 14, 2024, https://www.samhsa.gov/about-us.

218 SAMHSA, *Strategic Plan 2023-2026,* 2023, at 24, https://www.samhsa.gov/sites/default/files/samhsa-strategic-plan.pdf.

219 Aging Majority staff last searched the SAMHSA strategic plan on June 9, 2024.

220 E-mail from SAMHSA to Aging Majority staff, December 6, 2023, (hereinafter "December 6 SAMHSA E-mail"), (on file with the Committee).

221 *Id. See also* "Meaningful Stuff: Understanding, Assessing, and Addressing Hoarding," E4 Center, March 1, 2023, https://e4center.org/calendar/considerations-for-hoarding-in-older-adults/. The webinar was not recorded, but SAMHSA did provide a copy of the slides, which are on file with the Committee.

222 *Supra,* note 220, December 6 SAMHSA E-mail; "Managing Hoarding Disorder and Hoarding Behavior in People with SMI," SMI Advisor, July 28, 2023, https://smiadviser.org/events/managing-hoarding-disorder-and-hoarding-behavior-in-people-with-smi.

223 E-mail from SAMHSA to Aging Majority staff, April 23, 2024, (on file with the Committee); *Supra,* note 185, NCA Hoarding Webinar.

224 E-mail from SAMHSA to Aging Majority staff, May 21, 2024, (on file with the Committee); "Introduction to Hoarding Disorder," HHRC, June 5, 2024, https://hhrctraining.org/events-webinars/webinar/41708/introduction-to-hoarding-disorder.

Administration for Community Living

The Administration for Community Living (ACL) seeks to "maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers."[225] The ACL website includes a list of resources on mental health, but a review by Aging Majority staff found nothing specific to HD.[226] The ACL website also includes a page of "Reports to Congress and the President."[227] Aging Majority staff searched for "hoard" in Older Americans Act (OAA) reports to Congress from 2011 through 2018 and turned up no results.[228] Similar searches of Elder Justice Coordinating Council (EJCC) reports posted on the website for 2014, 2016, and 2018 also returned no results.[229]

ACL informed Aging Majority staff that ACL and its network has "been long aware of hoarding as an issue."[230] ACL further noted that the condition is often addressed by OAA grantees "at the state and community level."[231] However, ACL confirmed that it does not have technical assistance or documents that specifically address HD.[232]

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) is a "science-based, data-driven, service organization" that seeks to protect public health in the United States.[233] CDC's role includes detecting and responding to new health threats, using science and technology to prevent disease, and promoting health.[234] CDC's homepage includes an "A to Z" search tool that can be used to find CDC webpages on specific topics, including diseases or conditions.[235] Aging staff were unable to find a listing for "Hoarding" or "Hoarding Disorder" and were unable to find the condition under other relevant headers, such as

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225 "About ACL," ACL, last modified on September 29, 2020, https://acl.gov/about-acl.

226 "Behavioral Health," ACL, last modified May 9, 2024, https://acl.gov/programs/health-wellness/behavioral-health. Aging Majority staff last searched this page for the phrase "hoard" on June 9, 2024.

227 "Reports to Congress and the President," ACL, last modified on July 14, 2023, https://acl.gov/about-acl/reports-congress-and-president. Aging Majority staff last searched for the phrase "hoard" in OAA and EJCC reports linked to from this webpage on June 10, 2024.

228 Signed into law in 1965, the Older Americans Act provides grants to the individual states that help fund social services for older adults. The Administration on Aging within ACL oversees most OAA programs. *See* "Older Americans Act," ACL, last modified October 31, 2023, https://acl.gov/about-acl/authorizing-statutes/older-americans-act and Congressional Research Service, *Older Americans Act: Overview,* May 6, 2024, at 1, https://crsreports.congress.gov/product/pdf/R/R43414.

229 The EJCC was established by Congress to "coordinate activities related to elder abuse, neglect, and exploitation across the federal government." The Administration on Aging, within ACL, has responsibility for implementing the EJCC. *See* "Elder Justice Coordinating Council," ACL, last modified November 1, 2022, https://acl.gov/programs/elder-justice/elder-justice-coordinating-council-ejcc.

230 E-mail from ACL to Aging Majority staff, May 24, 2024, (on file with the Committee).

231 *Id.*

232 *Id.*

233 "About CDC," CDC, last updated February 12, 2024, https://www.cdc.gov/about/cdc/index.html.

234 *Id.*

235 Homepage, CDC, last accessed June 10, 2024, https://www.cdc.gov/.

"Mental Health" or "Aging."[236] CDC informed Aging Majority staff that the agency does "not have any information to share in this space."[237]

National Institutes of Health

The National Institutes of Health (NIH) serves as the medical research agency for the United States.[238] It includes 27 different Institutes and Centers with specific research agendas, including the National Institute on Aging (NIA) and the National Institute of Mental Health (NIMH).[239] Although some research is conducted on the NIH campus in Bethesda, Maryland, over 80 percent of NIH funded research is conducted through grants to external researchers.[240]

NIH maintains an online tool, RepORT Expenditures and Results (RePORTER) that can be used to search for NIH funded research projects.[241] Aging Majority staff searched RePORTER for the word "hoarding," and active projects funded by NIH. Aging Majority staff found four grants directly related to HD, two awarded in FY 22 and two awarded in FY 24.[242]

A representative from the NIMH informed Aging Majority staff that over the past five years, NIMH has supported eight projects that are directly focused on HD.[243] Three of the NIMH funded projects involve HD and older adults.[244] Of those three, one funds work to examine the effectiveness of CREST in treating HD.[245] A second funds work to examine the functional impact of HD on older adults.[246] The third funds work to test a new intervention for HD that combines motivational interviewing with sorting practice.[247]

Typically, fewer HD research projects are supported by the NIA than the NIMH.[248] A representative from the NIA stated that NIA is focused on HD as one factor among many

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236 "Mental Health," CDC, last updated January 25, 2024, https://www.cdc.gov/mentalhealth/; "Alzheimer's Disease and Healthy Aging," CDC, last updated June 29, 2023, https://www.cdc.gov/aging/index.html. Aging Majority staff last searched the CDC pages for the phrase "hoard" on June 10, 2024.

237 E-mail from CDC to Aging Majority staff, May 30, 2024, (on file with the Committee).

238 "Who We Are," NIH, last viewed June 10, 2024, https://www.nih.gov/about-nih/who-we-are.

239 "Organization," NIH, last updated February 7, 2023, https://www.nih.gov/about-nih/who-we-are/organization; "NIH Organization," NIH, last updated June 14, 2018, https://www.nih.gov/about-nih/what-we-do/nih-almanac/nih-organization.

240 "Organization," NIH, last updated February 7, 2023, https://www.nih.gov/about-nih/who-we-are/organization.

241 "RePORT: Research Portfolio Online Reporting Tools," NIH, last accessed June 10, 2024, https://report.nih.gov/.

242 Aging Majority staff last searched for "hoarding" through the RePORTER on June 12, 2024.

243 NIH Zoom meeting with Aging Majority staff, May 29, 2024, (hereinafter "May 29 NIH Meeting").

244 *Id.*

245 "Cognitive Rehabilitation and Exposure Therapy for Veterans with Hoarding Disorder," NIH, last viewed June 10, 2024, https://reporter.nih.gov/search/oiQhEz6rHE6EvvrWbCPRcg/project-details/10179338.

246 "Hoarding Disorder in Older Adults: Cognition, Etiology and Functional Impact," NIH, last viewed June 10, 2024, https://reporter.nih.gov/search/Bndk1Fe2MEaXBviGr8t0fg/project-details/10429983.

247 "Motivational Interviewing to Enhance Behavioral Change in Older Adults with Hoarding Disorder," NIH, last viewed June 10, 2024, https://reporter.nih.gov/search/IG8DmX9US0mptTPYz7Y44Q/project-details/10436587.

248 *Supra,* note 243, May 29 NIH Meeting.

that affects health and aging across the lifespan.[249] NIA also informed Aging Majority staff that NIA receives few research grant applications that are focused on HD.[250]

Department of Housing and Urban Development

The Department of Housing and Urban Development (HUD) is "responsible for national policy and programs that address America's housing needs, that improve and develop the Nation's communities, and enforce fair housing laws."[251] As noted previously in this report, people with HD are entitled to reasonable accommodation under the Fair Housing Act when facing eviction. HUD also plays a role in overseeing housing programs such as Section 8 certificates, housing vouchers, and public housing.[252] Assisted and public housing programs may, from time to time, address HD among their enrollees.

HUD's website includes information on discrimination under the Fair Housing Act. The information notes that discrimination based on disability (including "mental or psychological disorders") is prohibited and includes explanations on reasonable accommodation.[253] These are generally informative resources, but Aging Majority staff did not identify any references specific to HD.[254] HUD staff informed Aging Majority staff that local support services that address hoarding behavior qualify for funding through HUD's Community Development Block Grant Program.[255] HUD also referred Aging Majority staff to two online documents that briefly mention hoarding behavior. One document is a HUD tip sheet on readiness and response for building fires, and the second is a presentation by the Housing Opportunities for Persons With AIDS (HOPWA) Program.[256]

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249 *Id.*

250 *Id.*

251 "Questions and Answers About HUD," HUD, last accessed June 9, 2024, https://www.hud.gov/about/qaintro.

252 *Id.*

253 "Housing Discrimination Under the Fair Housing Act," HUD, last accessed June 10, 2024, https://www.hud.gov/program_offices/fair_housing_equal_opp/fair_housing_act_overview#_Who_Is_Protected?; "Reasonable Accommodations and Modifications," HUD, last accessed June 10, 2024, https://www.hud.gov/program_offices/fair_housing_equal_opp/reasonable_accommodations_and_modifications#rights-and-obligations; "Frequently Asked Questions (FAQs)," HUD, last accessed June 10, 2024, https://www.hud.gov/program_offices/fair_housing_equal_opp/reasonable_accommodations_and_modifications/faqs; HUD, *Joint Statement of Housing and Urban Development and the Department of Justice: Reasonable Accommodations Under the Fair Housing Act,* May 17, 2004, https://www.hud.gov/sites/dfiles/FHEO/documents/huddojstatement.pdf.

254 Aging Majority staff last searched the sources cited in footnote 253 for the phrase "hoard" on June 10, 2024.

255 E-mail from HUD to Aging Majority staff, June 10, 2024, (on file with the Committee). Authorized by the Housing and Community Development Act of 1974, the Community Development Block Grant Program provides grants to states, cities, and counties for urban development programs. *See* "Community Development Block Grant Program," HUD, last updated May 31, 2024, https://www.hud.gov/program_offices/comm_planning/cdbg.

256 "Building Fires," HUD, December 2022, at 1, https://files.hudexchange.info/resources/documents/PHA-Disaster-Readiness-Response-and-Recovery-Building-Fires-Fact-Sheet.pdf; "Creating Low-Barrier, Client-Centered HOPWA Programs," HUD, June 20, 2023, at 26, https://files.hudexchange.info/resources/documents/HOPWA-Client-Centered-Practice-Series-Best-Practices-for-Low-Barrier-and-Client-Centered-Practices-Slides.pdf.

United States Fire Administration

The United States Fire Administration is part of the Federal Emergency Management Agency (FEMA).[257] Specific Fire Administration efforts include reducing fire deaths through data collection, research and training, and public education.[258] Because cluttered environments are a fire hazard, hoarding behavior is relevant to the Fire Administration's mission.

The Fire Administration maintains a webpage on "Hoarding and Fire Safety," which is one of several pages targeted to "at risk" audiences.[259] The Fire Administration's "Hoarding and Fire Safety" page provides a brief description of HD.[260] It also describes how cluttered conditions are difficult for firefighters, provides tips for making a cluttered environment safer, and provides a downloadable handout on hoarding and fire safety.[261]

The Fire Administration told Aging Majority staff that the Fire Administration publicizes its information on HD and fire safety through social media.[262] The Fire Administration shared it does not have funding to publicize the information in any other fashion.[263]

257 "About the U.S. Fire Administration," U.S. Fire Administration, last updated May 23, 2024, https://www.usfa.fema.gov/about/.

258 *Id.*

259 *Supra,* note 140, Hoarding and Fire Safety Webpage; "Audiences at Risk from Home Fires," U.S. Fire Administration, last updated April 1, 2023, https://www.usfa.fema.gov/prevention/home-fires/at-risk-audiences/.

260 *Supra,* note 140, Hoarding and Fire Safety Webpage.

261 *Id.*

262 U.S. Fire Administration Teams meeting with Aging Majority staff, March 26, 2024.

263 *Id.;* E-mail from U.S. Fire Administration to Aging Majority staff, June 9, 2024, (on file with the Committee).

Part VIII - Recommendations

Because hoarding disorder (HD) disproportionately impacts older adults, communities will likely see an increase in the condition as America's population ages. An increase in HD will have implications for public health, emergency responders, adult protective services (APS), aging services, and housing providers. It will also have implications for older adults who seek to safely age in place. Many local communities have already begun to respond to HD. The federal government should take the following steps to support local efforts and help older adults with HD.

Increasing support and education for people with HD, local communities, providers, and families

1. **SAMHSA and ACL should provide training, guidance, and technical assistance regarding HD**. Although HD is relevant to the mission of the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Administration for Community Living (ACL), neither agency identified programs specific to the condition. SAMHSA and ACL should develop training, technical assistance, and other guidance for social service providers, health care providers, and first responders on how to respond to HD. Technical assistance should include tips and training for professionals likely to encounter people with HD. Technical assistance should also include guidance for communities on establishing a coordinated, evidence-based response to HD - including best practices for forming and sustaining hoarding task forces.

2. **CDC should maintain resources on HD and hoarding behavior.** The Centers for Disease Control and Prevention (CDC) does not offer or identify any recent agency resources or efforts related to HD. CDC should maintain public and online resources for the condition, similar to the resources the agency provides for conditions such as Lyme disease or dementia.[264] Online resources should include evidence-based tips for family and community members on intervention and harm reduction for someone with HD.

3. **HUD should provide guidance and technical assistance on HD for landlords and housing assistance programs.** Aging staff were unable to identify any HD specific programs at the Department of Housing and Urban Development (HUD). HUD should offer technical assistance and training specific to hoarding behavior for landlords and housing programs. HUD training and technical assistance on HD should include an overview of the need to provide a reasonable accommodation

264 *See* "Lyme Disease," CDC, last viewed June 10, 2024, https://www.cdc.gov/lyme/ and "Alzheimer's Disease and Related Dementias," CDC, last updated October 26, 2020, https://www.cdc.gov/aging/aginginfo/alzheimers.htm.

to people with the condition. It should also include tips and evidence-based best practices for intervention, including harm reduction.

4. **CMS and Congress should explore ways to expand Medicare and Medicaid Coverage for treatment and services related to HD.** HD disproportionately impacts older adults, many of whom are enrolled in Medicare or are dually eligible for Medicare and Medicaid.[265] The Centers for Medicare and Medicaid Services (CMS) should encourage coverage for evidence-based treatments and services through state Medicaid programs and explore ways to expand coverage for those efforts through Medicare. Congress should work with CMS on this effort and consider legislation as necessary.

Improving tracking, data collection, and research related to HD

1. **Federal agencies should increase and improve tracking of how hoarding behavior impacts older adults.** More data are necessary to understand how people are struggling with HD, particularly older adults. The federal government should seek ways to improve data collection and tracking for when hoarding behavior plays a role in confirmed cases of self-neglect for older adults. The federal government should also track how hoarding behavior hinders the provision of services through federal programs such as the Older Americans Act (OAA), Medicare, and Medicaid, and the role hoarding behavior plays with problems such as isolation, malnutrition, and falls.

2. **CDC and the United States Fire Administration should increase and improve tracking of how hoarding behavior impacts first responders.** Additional data are also necessary on how hoarding behavior impacts emergency responders. For example, CDC, the Fire Administration, and related agencies should seek to better track and understand data on how hoarding behavior impedes efforts to respond to medical emergencies. CDC and the Fire Administration should also seek to improve the Nation's understanding of how hoarding behavior contributes to fires and fire injuries, including the reasons behind any significant changes in reported data.

3. **NIH should continue to support research into hoarding disorder.** Significant efforts to research HD at all only began in the early 1990s, and HD has only existed as an independent diagnosis since 2013.[266] The National Institutes of Health (NIH) should remain vigilant for opportunities to promote evidence-based research into HD, including research related to etiology, impact, and effective interventions. The

265 CMS reports over 67 million people enrolled in Medicare. Over 89 percent are age 65 or older. Meanwhile, the Medicaid and CHIP Payment and Access Commission (MACPAC) notes that, in 2019, there were 12.2 million beneficiaries who were dually eligible for Medicare and Medicaid. 62 percent were age 65 or older. *See* "Medicare Monthly Enrollment," CMS, last updated May 31, 2024, https://data.cms.gov/summary-statistics-on-beneficiary-enrollment/medicare-and-medicaid-reports/medicare-monthly-enrollment. *See also* "Dually Eligible Beneficiaries," MACPAC, last accessed June 14, 2024, https://www.macpac.gov/topics/dually-eligible-beneficiaries/.

266 Randy O. Frost, "Hoarding: Making Disorder an Official Disorder," *Insight,* September 14, 2012, https://www.smith.edu/insight/stories/disorder.php#.

National Institute of Mental Health (NIMH) and National Institute on Aging (NIA) should also consider convening interested parties to discuss HD and older adults. Because robust funding allows NIH to support a greater number of new research proposals each year, Congress should ensure that it routinely appropriates enough money for NIH.[267]

Expanding recognition of HD and people living with the condition

1. **CDC should promote public awareness of HD and hoarding behavior.** CDC should implement a public awareness campaign to address HD and hoarding behavior. CDC's campaign should seek to educate the public on the causes of HD and other hoarding behavior and aim to dispel rumor and stigma. CDC's public awareness campaign should elevate the voices of older adults and others who struggle with the condition. It should also direct people with HD, their family members, and their communities to CDC and other federal resources on the condition

2. **Federal agencies and Congress should seek input from people with HD and their family members.** When considering new programs or initiatives, Congress and federal agencies should take steps to include people with HD and their family members in decision-making. Agencies should establish procedures for collecting feedback from people with HD and their family members when establishing new outreach and technical assistance programs. Congress should likewise seek their input for new legislative proposals and find other ways to elevate their voices.

267 One analysis notes that many NIH grant awards are multi-year. Consequently, NIH enters each year with existing projects that it is obligated to fund. If NIH is flat funded by Congress, it means that there is less money to go around for new medical research grant applications - including new proposals related to HD. *See* Mike Lauer, "How Grant Success Rates Do (Or Do Not) Track With the NIH Budget: A Model of Funding Dynamics," National Institutes of Health, March 25, 2024, https://nexus.od.nih.gov/all/2024/03/25/how-grant-success-rates-do-or-do-not-track-with-the-nih-budget-a-model-of-funding-dynamics/.

Conclusion

Hoarding disorder (HD) is a serious mental health condition that causes people to accumulate more objects than they need. Although HD can impact people of any age, prevalence and severity are greater among older adults. HD impacts roughly two percent of the general population, while it impacts about six percent of those over the age of 70.[268]

HD also has serious consequences. For older adults, those consequences include health and safety risks, social isolation, eviction, and homelessness. For communities, those consequences include public health concerns, increased risk of fire, and dangers to emergency responders. Local communities throughout the United States are already working to address cases of HD, including through the formation of hoarding task forces to coordinate response efforts. Unfortunately, the resources available for local responses often do not correspond with the level of challenge communities are facing.

The United States is aging rapidly, and older adults are expected to make up nearly a quarter of the population by 2060.[269] That population shift will require the federal government to address issues that it has not previously prioritized. HD is an example, as communities everywhere can expect to see a growing number of cases as America ages. Although some federal agencies have taken steps to address HD, those steps are frequently limited. Other relevant agencies have not addressed HD at all in recent years.

Our Nation must be prepared. One 80-year-old who has struggled with HD for years discussed how we can tackle the condition together:

> Being positive, listening, and hearing are very helpful. People often make negative remarks, and that doesn't help a thing. People think everything should be under control, and you only have yourself to take care of, and that's my priority because you can do it and do it well. It's hard, physically, to do the things I used to do. I can't work as quickly as I used to.
>
> What we need are more people out there willing to listen and help, making good suggestions, being positive. It's important to help people who clutter to know that there's help, they're not in this alone, there's lots of people in this situation.[270]

268 *Supra*, note 3, Postlethwaite Prevalence Article; *Supra,* note 4, Age Prevalence Article.

269 *Supra,* note 54, Census Aging Population Article.

270 *See* Appendix B, Statement from Maureen in Connecticut, at B-020.

The federal government can, and should, do more to bolster the response to HD. This report included recommendations that will allow the federal government to address HD in a proactive and compassionate fashion. If followed, the recommendations will improve the data available to shape the government's response. The recommendations will also enhance the federal government's support for people with HD, their family members, and their local communities.

Appendix A - Request for Information

To better understand the impact of hoarding disorder on local communities, Aging Committee Majority staff submitted a request for information (RFI) to relevant stakeholders. The RFI was sent directly to non-profits, social services organizations, and state and local governments. It was also disseminated through professional organizations.

Hoarding Disorder Request for Information

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510–6400
(202) 224–5364

March 19, 2024

To interested parties:

Hoarding disorder (HD) is a chronic and progressive condition that leads people to accumulate more objects than their homes can accommodate.[1] HD impacts people of all ages. However, the prevalence of hoarding appears to be significantly greater for older adults (roughly 6.2 percent) compared to younger adults (roughly 2 percent).[2] The severity of hoarding behaviors exhibited by people with HD also generally increase with each decade of life, even as those behaviors typically emerge before the age of 20.[3] Accordingly, some of the most severe cases of HD are among older adults.

The disproportionate prevalence and severity of HD among older adults has implications for our rapidly aging Nation. By 2060, the number of older adults in the United States is expected to increase by 40 million people compared to 2019.[4] Because HD disproportionately impacts older adults, experts worry that aging "could fuel a rise in hoarding."[5] Local governments, emergency responders, and social service organizations are already witnessing the impact of HD on communities throughout our country. Those same groups will serve on the front lines of our response as HD becomes more common – yet it appears that their needs for addressing HD have received limited attention from Congress.

[1] David F. Tolin and Anna Villavicencio, "Inattention, But Not OCD, Predicts the Core Features of Hoarding Disorder," *Behaviour Research and Therapy* 49, no. 2 (February 2011), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3038586/.
[2] David M. Roane et al., "Hoarding in the Elderly: A Critical Review of the Recent Literature," *International Psychogeriatrics* 29, no. 7 (2017) at 1080.
[3] Linda M. Richmond, "Despite Addition to DSM, Few Treatments Emerge for Hoarding Disorder, *Psychiatric News*, January 31, 2022, https://psychnews.psychiatryonline.org/doi/full/10.1176/appi.pn.2022.1.18.
[4] "Promoting Health for Older Adults," Centers for Disease Control and Prevention, last reviewed September 8, 2022, https://www.cdc.gov/chronicdisease/resources/publications/factsheets/promoting-health-for-older-adults.htm.
[5] Rose Conlon, "Hoarding May be Increasing Because of Aging Population, Scarce Mental Health Care," *NPR*, September 7, 2023, https://www.npr.org/2023/09/07/1198065591/hoarding-may-be-increasing-because-of-aging-population-scarce-mental-health-care.

The Senate Special Committee on Aging is charged with studying "any and all matters pertaining to problems and opportunities of older people," including problems related to health, housing, care, and assistance.[6] HD, and its potential impact on communities and older adults in the coming decades, intersects with all of those issues. Accordingly, the Committee is seeking information from stakeholders related to the impact of hoarding disorder.

Please e-mail written responses to the following inquiries to HoardingDisorder@aging.senate.gov no later than midnight on April 15, 2024. Please note that this request is voluntary, and that your responses may be referenced or shared as part of future Aging Committee efforts.

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

If feasible, please share data and primary source information related to the rate and impact of HD on your organization and community.

Thank you for your help with this matter. If you have questions about this request, please reach out to Doug Hartman on the Aging Committee staff at [redacted]

[6] "Rules," United States Senate Special Committee on Aging, last accessed March 19, 2023, https://www.aging.senate.gov/about/rules.

Appendix B - Statements

Aging Committee Majority staff collected statements from people with hoarding disorder (HD), academic experts, firefighters, social service providers, elected officials, and other interested stakeholders. Some stakeholders submitted statements in response to the request for information included in Appendix A. Others submitted statements in response to a direct request from Aging Committee Majority staff, or through a peer-organization or counseling group. Appendix B includes a sample of the statements submitted to Aging Committee Majority staff.

The names of some of the people with HD have been changed to protect their privacy.

Statement from Anonymous

Submitted on May 31, 2024

I am very grateful to have the opportunity to share my story about my experience with Hoarding.

I am a 67-year-old African American widow. As a child my house was chronically in a state of chaos from clutter and hoarding. I subsequently grew up with minimal to no capabilities to organize my own home as an adult.

So, hoarding and clutter has been a way of life for me with debilitating consequences:

I have never been able to have company because my house has always been a complete disorganized mess. This fact has caused me to live in sadness and isolation--certainly not a good state to be in as a senior citizen!

Also, it has always been an impossible experience for me whenever it comes time to look for important documents. The agony of searching for important papers when I need them has many times been unbearable, as I oftentimes can't find them in the mess.

I would like to request that the government provide funding to create opportunities for people to become Hoarding Counselors and Specialists, as it is a dire need. Severe depression often is an outcome from living in hoarding situations.

Please consider my request very seriously.

Thank you.

Anonymously Submitted

May 31, 2024

Statement from Deborah in Massachusetts

Submitted on April 25, 2024

Dear Mr. Hartman and Committee Members,

Thank you for the opportunity to share my story of my very real struggles with clutter and hoarding in an effort to help social service agencies, especially agencies serving our elderly populations, see the very real need for support, and for them to receive the necessary funding to provide that support.

I was always a “neatnik” growing up. I was raised in a neat, orderly, clean and sanitary household. Throughout my college years and into my 20s and 30s, I continued to be neat and organized. I enjoyed keeping my place well. It was also well designed, as I am a graphic designer by trade. I didn’t have a problem with having too many things, nor a problem taking care of my things. My sense of design showed in my surroundings. A friend said my place “looked like a museum”.

But in the year 2000, when I was 40 years old, I was in a relationship which ended badly, the man was abusive to me, there were legal entanglements, I was subpoenaed to probate court. The whole incident was very traumatic for me and I sought counseling at a local domestic violence agency.

It was after that chapter in my life that I began to have a clutter problem. I acquired too many things and couldn’t keep it all in an orderly fashion. Inanimate objects that brought joy replaced people who hurt me. I also moved several times within a short period of time, I had housing instability and my income dipped substantially. I became depressed, anxious, unable to earn enough income to support myself. I was evicted three times for non-payment. I finally applied for, and was approved for, SSI disability.

In 2011, I got very sick, was bedridden and nearly died, from what was eventually diagnosed three years later as chronic Lyme Disease. I was also getting sick from excessive mold in some of the places I lived. These illnesses caused neuropsychiatric symptoms in addition to physical symptoms. I could not think straight and my executive functioning sunk to new lows. My health is still very compromised and I continue to be on SSI, combined now with SSA retirement. My income is way below poverty level.

I am of above average intelligence, I am proactive, a good networker and not someone who just sits around being lazy and feeling sorry for myself. I strive to find solutions. When I learned about, and signed up for the Buried In Treasures course, based on the book “Buried In Treasures, Help for Compulsive Acquiring, Saving and Hoarding”, and had the good fortune to work directly with Randy Frost, one of its authors and founders of the workshop, I felt a surge of hopefulness.

Lee Shuer, a wonderful teacher trained by Randy directly, has been the facilitator of my specific class. I have taken the BIT course three times now, and although I have found it very helpful,

each time being reminded of better strategies, the end result is that I have found it still difficult to implement the strategies by myself. My physical and mental abilities are simply too limited. I have realized that I need help from someone who *understands* cluttering and hoarding and can enhance my efforts with appropriate trauma-informed hands-on help.

I am now 64 years old. When I turned 60, I became eligible for home care help from the local eldercare agency. The way they work is to outsource clients' home care needs to a 3rd party agency, whose managers would come do an interview, I would make it clear what kind of help I needed, yet over and over again, they would send workers who had no idea how to deal with my clutter and hoarding, after they assured me their workers were trained in this. I would complain, they would send another and another, every time ending in disappointment and frustration. They could do general cleaning, did laundry and meal prep, but none of the deeper work I needed help with. Most of the workers were young and inexperienced even with those chores. Some seemed genuinely disgusted having to learn anything new. It became very frustrating and eventually I said enough, this is not working, please stop sending people into my home. This got me more depressed, and the clutter problem got worse. Meanwhile, please know, I live alone, and the clutter/hoarding problem was the number one reason to not have anyone visit my home.

Then, I was so grateful, the eldercare agency told me that they would give me $500 in grant money to find my own help. So, I gladly asked Lee Shuer if he would help me, and he gladly accepted. Lee has been a blessing to me. Not only did he already know me and my story, but at the point I could hire him, he already knew I was facing a no-fault eviction, and he was able to help me make well-founded decisions about organizing, giving/throwing away, and packing up boxes to go to my storage unit.

I am now homeless and couchsurfing, but Lee has truly been a great gift during this process. And now, he has asked me to write this statement for you, for which I am honored.

Summary:
* I never had a problem with clutter and hoarding when I was younger. The problem started after a traumatic event at age 40. It was like a switch was turned on, and it has not shut off.
* I have tried for a few decades to deal with the problem myself, with some success but mostly failure.
* The Buried In Treasures course helped me a lot, but not enough. It is validating to talk with fellow clutterers and hoarders, and share our struggles and stories.
* I struggle with OCD/ADD as well as depression, anxiety and physical health limitations. I have undiagnosed post-concussion syndrome and increasing memory problems.
* Many of us clutterers and hoarders need someone to work alongside us, to buddy up to do hands-on trauma-informed work. Many times, I need help with just making an efficient decision, without overthinking it.
* Hoarding is in the DSM as a mental health diagnosis. Therefore, those afflicted/diagnosed should get help from trained professionals with mental health expertise.
* As a mental health diagnosis, trained help with cluttering/hoarding issues should be covered on our health insurance, just as other mental health treatments and interventions are covered. Proper diagnosis should be made, and treatments planned accordingly.

* My struggles with clutter and hoarding have greatly contributed to my reluctance to have visitors to my home. This causes social isolation and adds to my depression, which then causes more problems with clutter and hoarding. This is a viscous cycle.
* The eviction has left me couchsurfing and I have no permanent housing in sight. This chronic housing insecurity causes me emotional pain and grief, which fuels the cluttering and hoarding.
* My family and some friends stigmatize my struggle, making it worse.
* I feel it is time for this mental health issue to get the validation it needs. We need a public health campaign to portray it in a light that elicits empathy and support, not vindication.
* When we get help, and our spaces are cleared and organized, we have a lot happier, healthier version of ourselves to offer the world. And isn't that what the world needs?
* Thank you again for taking interest in this issue and inviting us to tell our real stories.

Sincerely,

Deborah

Statement from Gia in Texas

May 31, 2024

Douglas Hartman
Research and Policy Analyst
Chairman Bob Casey
U.S. Senate Special Committee on Aging
G-16 Dirksen Senate Office Building
Washington, DC 20510-6400
202-224-5364

I am a 57-year-old woman living in rural Texas. My journey with Hoarding Disorder stemmed partially from heredity; both of my parents hoarded, mom inside the house and dad outside. We have a standing joke in my family about a set of wheels my father kept for decades. He was going to make a cart out of them. He never did. Now, when family members encourage me to release items I have held on to for far too long, they ask me “Are you going to make a cart out of that?” My mother’s drug of choice was household decorative items: lamps, figurines, glassware, candlesticks, etc. etc. Until the day she died, she lived with the delusion that nothing she had could ever be replaced, so she felt she needed to keep everything. In addition to my ancestral history, my specific trigger for Hoarding Disorder was a house fire when I was eight years old.

In 2000, I developed relapsing-remitting multiple sclerosis. This condition reduces my physical strength and stamina, making it very difficult for me to lift, carry, and sort the possessions I have hoarded. Relapses render me essentially bedbound. However, the most significant factor complicating my recovery from Hoarding Disorder is that I was born legally blind. Having low usable vision only in one eye means that when I look at a pile of hoarded items, it looks two-dimensional to me; I am unable to visually distinguish the individual items. My limited vision causes me to underestimate how much stuff I actually have. Furthermore, if I lose something, I can’t “just look for it.” This limitation prompts me to purchase multiples of the same item. Losing an expensive pair of specialized reading glasses that I need to do my job finally prompted me to seek help from a mental health clinician who specializes in Hoarding Disorder.

Because of my disabilities and need for a driver and personal care attendant, I live with my brother and sister-in-law, who fills these roles and also serves as my de-hoarding coach. We currently live in a small, single-wide mobile home in rural Washington County, Texas. My continued hoarding of this space before I began treatment compromised our safety and that of our beloved pets, as well as the functionality of our small home. Therefore, my “overflow” ended up in our carport, drawing unwelcome attention from our neighbors and landlords.

The clinician’s support, along with the workbook *Treatment for Hoarding Disorder* by Gail Steketee and Randy O. Frost, enabled me finally to change my mindset and start making progress toward recovery. Through treatment, I have been able establish and

maintain acceptable, though still not ideal, safety inside the trailer, and have cleared two-thirds of the mess outside. My biggest obstacle in completing the process is a **lack of physical help**, which is not available in my area at any cost. My relatives are not able to help me in this way because of their own disabilities.

While researchers and clinicians recognize the effects of comorbid mental disabilities, such as anxiety and depression, on those with Hoarding Disorder, not enough attention and resources focus on **physical comorbidities**, such as low vision and multiple sclerosis. My motivation for participating in this testimony is **to attract attention to and funding for Hoarding Disorder treatments, including physical and occupational therapy, that address physical comorbidities**. I further wish to advocate that increased resources be made available to those living in **rural communities**.

Statement from Jean in Massachusetts

Submitted on May 3, 2024

Dear Mr. Hartman and Committee Members,

I didn't think I had a hoarding disorder. I knew that I had accumulated a lot of stuff over the years and didn't know what I was going to do with it as I was becoming more and more unable to process all I had accumulated. It soon became more than anyone could handle by themselves. After accumulating so many unnecessary items, I became unable to clean-out. It was difficult to find a spot to begin with.....so overwhelming!!

With help, which in my case was and still is extremely necessary, I am finally seeing the path to a better way to live.

Sincerely,

Jean
80-year-old female in MA

Statement from Jess in Pennsylvania

Submitted on May 31, 2024

My hoarding started when I went to school to teach. I needed materials, so I used to keep everything that I could think of that I knew could be great for a lesson plan. This could be scraps of paper to pieces of foil just so the kids could have better learning skills than just reading.

From there, I had too much in my bedroom at the time. I created a basement storage area for the extra material. That was in Pittsburgh. When I came to Philadelphia, I continued teaching and I needed more supplies. Then it became overwhelming and very messy. Those things ended up in boxes and containers. Then I had an abundance of containers full of items. I decided I needed large rubber containers to put them in. Even though I was using the supplies, I still had a lot. Then I had a physical injury that prevented me from keeping up with the organizing of my apartment. I had medical issues where I could not stand. I went from an organized environment to an environment that just had items in more boxes and more boxes.

It has impacted my life because, even though I am going through the boxes now, I don't have a study. I can't use my table. I can't type. I want to write but I can't write. I have to go on my couch to write, I can't go into my room to write. I am wasting money on a storage unit. And I have two storage units in the basement. I persuaded the landlord to give me two storage units rather than one, like the other tenants. I am too embarrassed to have people come and visit me. When I visit people, their space does not look like mine. I am clean, I am neat. But I just have this extra tension, anxiety, and overwhelming stuff that I need to go through. I want to befriend this woman I met recently, and she wants to come over. I don't know what to do! I always go to people's homes, so people don't know what my home looks like. I want her to come over, I want to swallow my pride. But it is very difficult, and I most likely will meet her outside, if I meet her. So I lack friendships. I always want to open my door and just say, just come by no problem, you don't have to call, just come. But I can't do that because of my many boxes. So it is a hindrance.

I wish other people would understand that there are ways to educate individuals. With support, like my JFCS hoarding case manager and my other support groups, I understand that this physical situation has psychological aspects. There should be treatments out there, with no drugs or physical pain, that should be given to individuals that may need it. Because it is a psychological process, and it should be addressed that way. People should be given the opportunity to grow, beyond from where they are now, to something healthier and better for themselves. And then you will have a healthier society.

Maybe there should be groups of people studying this matter, the hoarding situation, scientifically.

Statement from Kathy in New York

Submitted on April 15, 2024

Dear Mr. Hartman and Committee:

I have a family history of Hoarding Disorder. I am an Office Manager, mom, and person struggling through this disorder and luckily I have an incredible desire to research and learn. I've found my own path to healing and am well on my way. I struggled to find help for Hoarding Disorder.. it was impossible to find.

I am not out there publicly as a support person for Hoarding Disorder as I try to protect my family and daughter from the shame that is attached to this disorder, but I'm known in many circles all over the world as I came out with my own Facebook group and started providing resources to people who were struggling. That is my main mission. We provide FREE or affordable resources to people who are struggling. Most doctors/therapists know nothing about this disorder. Even the ones who are researching it are finding it difficult to come up with effective treatment options. At this time, the best treatment is CBT therapy and many experts suggest the Buried in Treasures 16 week workshop and book.

I have done both and it seems to help. But it's not a cure all. I'm still slowly working through the psychological issues and that is helping me to let go of the clutter/stuff. The stuff was like a protection .. a security blanket when I felt unsafe.

This is what I've done and it seemed to help. I'm considering myself a guinea pig for researchers…

Therapy – We need Hoarding Disorder informed therapists available to people in all US states. Many are in California and are not available to treat people in other states.

Trauma - EMDR therapy for trauma – Many of us think that trauma is a big part of triggering Hoarding Disorder. I know it was for me… but I also have a family history too. It's like it was laying dormant in my brain until the multiple traumas happened then whammo. I am currently in EMDR treatment and it's helping tremendously.

Hypnosis – helping to reprogram the subconscious.

Tapping/EFT – helps to calm the brain so that we can think and get out of fight/flight

Meditation – same as above… calm the brain… I'm currently in a Meditation Teacher and Trauma Response Certification Teacher program.

Buried in Treasures Workshop and read the book 2x.

Self-Compassion Course – Self compassion and CFT seem to help. I've done a course on this and the self-compassion seemed to be the key to help unlock some of the shame and blame that comes with HD.

Started my own Hoarding Disorder Group on Facebook to share resources with others

Support groups – I attend at least 3 meetings a week. One is a training course with a Hoarding therapist/expert in Canada who provides weekly FREE meetings to help us as she feels horrible for the lack of treatment options for all of us. Elaine Birchall online.

I started having issues with Hoarding probably about 7 years ago and realized it had become a problem.

I did the Buried in Treasures 16 week workshop and book Nov 2020.

Started Facebook Group 8/8/21 to help others with my co-admin Oprah and we are up to almost 2,000 people now. We provide support and resources just to people struggling with Hoarding Disorder.. not family or friends. It's a place where people are safe and don't feel judged.

My Hoarding reared it's ugly head after a few major traumas in my life…(death of best friend, assault, sudden incurable disease) and I reached out to Dr. Gail Steketee, expert in Hoarding and author of many books on the subject and said how do I get help? She suggested that I try to attend the Buried in Treasures online group and individual therapy. Many of us have limited funds and this is a very complicated disorder that even the doctors have not been able to fully understand yet. A Buried in Treasures course is usually around $300 - $500.

Our Facebook support group is listed on the IOCDF site. The first week that my personal cell phone was listed on the IOCDF site I was flooded with calls… I have a FT job and a daughter and am not setup to handle this amount of inquiries. I asked the IOCDF to just list our Facebook group only and people can connect with me through that if they are looking for support. There are so many people looking for help. They feel alone and frustrated with the lack of help.

1.How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Quality of life diminished - Isolation, depression, anxiety, fear, guilt, shame, loss of hope, feeling alone and frustrated at the lack of care and programs for our disorder. Family shame and arguments as they don't understand the disorder either. We are not lazy… I used to have 4 jobs (2 of which were cleaning houses… We are not lazy).

Fear of calling for help when there is a medical emergency as first responders won't be able to access the person with the clutter in the way.

Fines – People are forced to pay fines from city inspections when they are already struggling. Forced quick cleanouts don't help. They can trigger the person to commit suicide and the hoard always comes back .. sometimes worse than it was before. This is never suggested.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Overwhelm – We are 2 people … dedicated to helping others with Hoarding Disorder as we know what it's like and we are passionate to find better help. We really need an International Hoarding Disorder Foundation dedicated to research and helping people with this disorder. California and the Mental Health Association of San Francisco seems to be leading the way the

best they can under the current restrictions. We need to allow therapy by experts nationwide … not just in the state they are licensed in. It's hurting the progress of treating this disorder.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

No guidelines – We have zero guidelines as a private Facebook group. We can share any/all treatment options without fear of being sued or having funding pulled. Some of the laws that states have to follow when providing therapy is really slowing things down. We share all hoarding informed programs on our page.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

MORE RESEARH on Hoarding Disorder please. There have been very few studies. It was misclassified in the DSM-5. Suggested treatment from experts is now CBT therapy and the Buried in Treasures workshop and book based on CBT. More studies need to be done on additional therapies such as CFT Compassion Focused Therapy and other forms of treatment. The current therapy is not that effective.

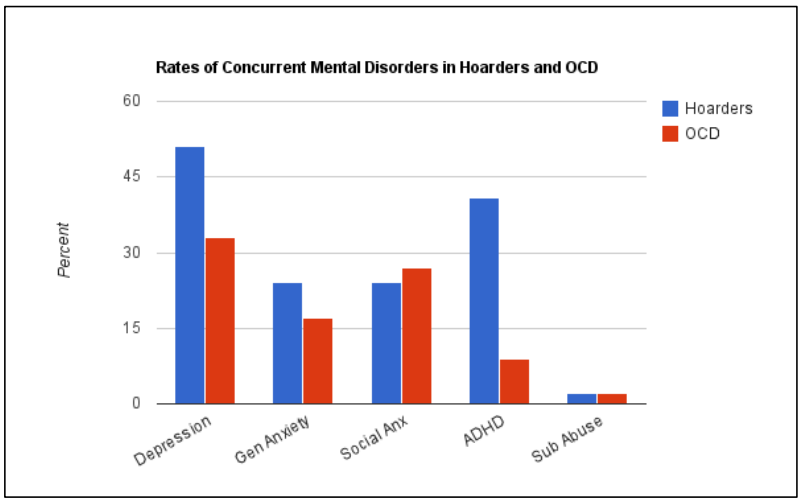
Advocates – Provide a state funded advocate to help the person with HD find therapy, courses, and support groups to assist in recovery.

CPS and Adult Services – Many people with HD are afraid of eviction. Training for landlords and others on Hoarding Disorder so they know that it's a mental illness and that we are not just being lazy. Give them training so people with HD don't fear reaching out for help. This causes many to stay silent and stuck. They fear getting kicked out, inspected or fined.

Cleaning – Affordable programs for cleaning and coaching from people who were trained in Hoarding Disorder. Many people just need a helping hand. Someone who is able to do the work, lift, move, clean at the instruction of the person with HD.

Cleanouts – Cost can be $20,000 just for a basic trailer plus fees for travel, etc.

Comorbidities: Many of us suffer with other issues such as depression, anxiety, ADHD, PTSD, bipolar and as we age issues with back, mobility, knees hindering daily maintenance.



Note: Chart is adapted by statement author from data presented in Frost RO, Steketee G, & Tolin DF (2011). Comorbidity in Hoarding Disorder. Depression and Anxiety. PMID: 21770000.

Fire Departments – Training on our disability so they can respond with kindness, compassion and understanding vs. judgement and hostility.

Isolation – Can't have friends and family over. Depression gets worse as the clutter gets worse.

Physical help - from nonjudgmental advocate

Repairs – Many don't call for repairs because house is so bad. We go years without working sinks, heat, toilets, electrical, etc. Many of our elderly are suffering through winters in the cold and use unsafe heating options vs. calling for repairs. Have programs that train electricians, HVAC, plumbers on our disorder.

Therapy – not affordable for many people. There are VERY few therapists who know anything about Hoarding Disorder.

Who am I: An Office Manager, mom, sister, daughter, volunteer

What am I passionate about: Fishing, paint, volunteering, research, helping others

What do I struggle with: Hoarding Disorder, Anxiety, Depression, and PTSD

What do I need: I need help with this MASSIVE worldwide struggle with this disorder. California (MHASF) has AMAZING free resources… other places do not… We are really having a hard time serving all of the people who need help with this.

People are afraid to come forward and seek help – Would you seek help if you may be evicted, or your children might be taken away? Probably not… You would stay in your home.. with your depression, anxiety, and overwhelming feelings as things got worse and worse..

How to pass an inspection from CPS or Adult Protective Services. Help with main priorities – safety … fire hazards, pathways, safe heat sources.

HD is a protected disability. We need reasonable accommodations for certain issues: eviction, meeting deadlines, etc.

Therapists who specialize in Hoarding Disorder are NOT ALLOWED to treat people in other states … this in my opinion is one of the BIGGEST struggles … I found ZERO people in NY with experience in Hoarding Disorder so therefore not covered under my insurance..

Elaine Birchall, therapist in Canada …. provides us with FREE weekly meetings for people who struggle with HD and is OVERWHELMED with requests.. She is doing the best she can as 1 person … helping each week. Dr. Chou also provided our community with some FREE You Tube sessions. That's it.. for FREE and affordable help.

My favorite experts in this area:

Dr. Randy Frost

Dr. Gail Steketee

Dr. Tolin

Dr. Chi-Ying Chou

Dr. Susie DuBois

Dr. Carolyn Rodriguez

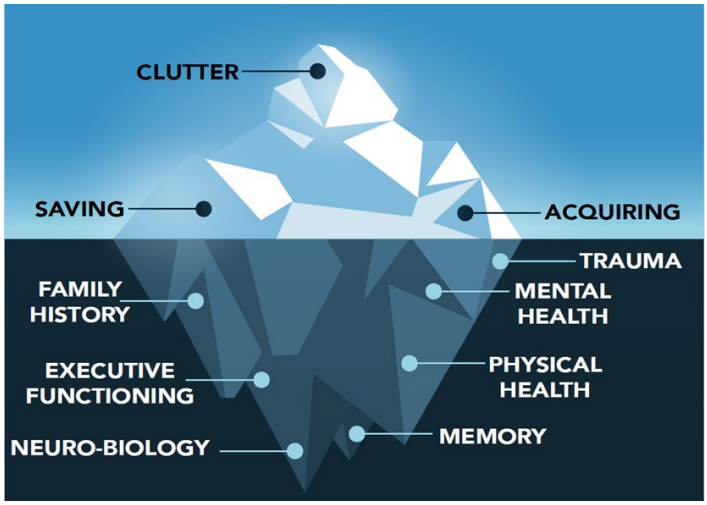
Elaine Birchall, MSW, RSW – Canada

Dr. Jan Eppingstall – Australia/PhD in Psychology with Hoarding Disorder Focus

Lee Shuer – Peer expert.

Please help us to provide the needed support to those who are struggling. HD effects an estimated 2 – 6% of the population (1 in 40 people some say). Some expect the number to be higher as the stigma of this disorder keeps people from coming forward for help. Men and women are almost equal at similar rates. It impacts all races, ethnicities and cultures around the world. Many of the people in our group are teachers, first responders, therapists…

This is one of my favorite graphics from our support groups. What people see with HD is the clutter.. the saving … the acquiring. What you don't see are all of the other mental health struggles that can go along with Hoarding Disorder. I could add about 10 – 20 more bullets under the water.



We need your help. I am available for any questions. We volunteer for any/all research programs to help find a better way.

Respectfully,

Kathy

Statement from Ken in Washington state

Submitted on May 31, 2024

To: Congress
Re: Hoarding Disorder

My hoarding is a result of a desperate effort to soothe or calm an exaggerated sense of anxiety and shame and a weird fear of people. If there was a word that goes beyond shame I don't know what it is, but that is what I often experience, and it keeps me from socializing. I'm 62 and it is only recently that I've discovered that my early experiences of being severely neglected by a mother with deep depression, constant ridicule by a father and older siblings (I'm the youngest) has resulted in a deep mistrust of my ability to have any close relationship, and often a profound discomfort of being around people. Acquiring things is an effort to replace relationships, but will never ultimately be satisfying and so continues, sometimes at a financial stress.

I liken hoarding to an addiction of any kind. In this case it is a behavioral addiction and not a substance use addiction. Ironically, when financial stress adds on to my underlying anxiety, I will sometimes buy even more things and just get into more financial difficulty. I hate this about myself because it is the opposite of common sense and then things just get worse, like any addiction. Many hoarders are also likely to have other addictions as well.

Just stopping the behavior of any addiction reveals the intense emotions that underly addiction. A feeling of being overwhelmed and fearful/ anxious is often my base state, and feeling this brings on a deep state of shame, and often depression and uselessness. Not being able to keep a job or to clean are not a result of laziness, it's a result of feeling useless.

Some things I think that would be helpful as government support are:

1. recognition that, like any addiction, hoarding is a desperate response to an underlying psychological condition
2. weekly support groups
3. individual case worker
4. financially supported removal of hoarded material.

Thank you for the opportunity to speak about this condition.

Ken

Statement from Lindsay in Pennsylvania

Submitted on May 31, 2024

Senator Bob Casey,

Here is my history as an adult with a hoarding disorder.

As far back as I can remember as a child, there were always things around; I am soon to be sixty-five years old.

It hasn't helped that we live in a three-story house with basement and attic.

My mother didn't throw out some of my baby clothes until I was older, and by then there were things all over the house (not as bad as it is now).

My mother worked until I was born and then stayed home. My father worked as a draftsman at Westinghouse. While I was criticized for not being able to get rid of things, it wasn't always visible. One would never know that my father had a hoarding problem because he was a neat-nick and had everything organized. I dread eventually going into my father's study a large room that has file cabinets, and many book shelves; right now that room is completely unaccessible.

I recently had to go into my former bedroom, because I was looking for a legal document and had previously looked someplace else. The problem was that there were things blocking that door (which can be accessed from the bathroom door or the hallway door). Originally, I was planning on removing stuff from in front of the door, but I came to the conclusion that that would take too long. I decided that I would open the door and climb over the stuff. Since I wanted to be on the safe side, I had someone on the phone with me. It was absolutely horrible!!! It was a complete disaster!!! Not only was the document not in there, it was still....

For now since I am unable to close the connecting door, I have too look at all those things. The plan is to put those things in a plastic bag, where I can eventually close the door (although anything I can throw out along the way, I do).

There is a room on the first floor that is completely unaccessible and has lots of furniture in it, and while there are things that will have to be sold, they do carry an emotional price.

That emotional price carries over into other things, in particular not being able to find important papers, such as bills, bank statements etc...

There is also a huge and unfortunately expensive problem since things have been in a storage locker, going on close to twenty years.

We would have lost our homeowners if things had stayed in the house.

This is my story, but not all of it.

Please feel free to contact me if you need or want additional information, pictures or talk to me over the phone.

Sincerely yours,

Lindsay

Statement from Maureen in Connecticut

Submitted on May 3, 2024

Dear Mr. Hartman and Committee Members,

Clutter has filled lots of spaces in my life.

In my younger years, lots of things I collected made life easier. I also saved things to look at and enjoy later; even though I haven't gone back to look at my archives, I continue to save new things that come in, and I have fallen behind.

After I had a fall and was in the ER, I wasn't at my best point and in need of recovery. The stress was too much at one time. The senior service person who works with housing was alerted by the EMT that had noticed a lot of stuff and was concerned about getting through to different areas. I told them I had been working on it but wasn't done yet.

Then the fire marshal responded and knocked on the door and when I didn't answer the door they thought I didn't want to let them in. I was asleep. They left a phone message for me to call them back, which I did. We arranged a time for them to come back and I did let them in because I recognized the need to declutter as well as they had.

Over the years I have had lots of losses and have accumulated things from family members and friends.

I was too busy to keep up with organizing. I had an ongoing project fighting the construction of a berm behind my property. That kept me busy for years, studying soil science and dealing with the city, so I was too busy to help myself. I spent hours and hours in the Planning and Zoning office reviewing all the paperwork that came through about the case. I wondered, "Could I fight city hall?" I had a lot of people in the faith community praying for the situation to improve to avoid getting poison water on my lawn.

Eventually I won.

I had bouts of depression but kept hanging in there. So while much of my time went to city hall, I was also a caregiver for my aunt for 30 years plus I had a full-time job.

I was a social worker and I worked in protective services when the laws were first passed in 1965 at age 21. I covered 36 towns in the north-central region of CT. I was a case worker, on call 24/7, which was too much with family members aging and not able to manage on their own.

Before I went to visit homes for the first time, I would never assume that the people had done whatever was reported, because it's better to go and see for yourself. I recognized the situations that the families were in. I found that I was able to work with all the families that I had because they trusted me. I would say, "I'm here to help you out." I know people appreciated it. One

person called her supervisor and said that she wanted the state out of her business, but that I could come back any time.

Being positive, listening, and hearing, are very helpful. People often make negative remarks, and that doesn't help a thing. People think everything should be under control, and you only have yourself to take care of, and that's my priority because you can do it and do it well. It's hard, physically, to do the things I used to do. I can't work as quickly as I used to.

What we need are more people out there willing to listen and help, making good suggestions, being positive. It's important to help people who clutter to know that there's help, they're not in this alone, there's lots of people in this situation.

Years ago, it wasn't called hoarding, it was called collecting. Then things went from collecting to hoarding.

We need to be more in tune with our friends, our family, and our neighbors. Notice if they are trying to do too much and unable to complete their tasks.

People used to say, "Gee, you've got so much going on, can I go over and take care of such and such while you do what you need to do." There was more community support, we had less and shared more. Our attitude was waste-not-want-not. Things were given to the next family who needed them.

I have seen the breakdown of the family unit and the breakdown of civilization. Years ago, you had more people trying to help each other.

I've lost more people in the last few years; I can't keep up making new friends.

It is great to know that someone wants to hear about this and to help seniors, or people of any age. If you can help people while they're younger, it's even better.

I remember a priest 10 or 15 years ago who said to do something for themselves first, because we can't help others if we wear ourselves out.

That's something we should have been taught earlier.

Hopefully,

Maureen

Female resident from CT
Now in her 80th year

Statement from Sally in Connecticut

Submitted on April 24, 2024

As a-65-year old woman in CT, my experience with hoarding has varied with time, circumstance, and stress. I grew up in a hoarded household in MA which got progressively worse. Although it was huge, several rooms in the house were completely unusable (physically challenging to enter) because of the volume of stuff they held, often stacked thigh-high or deeper. When my parents moved as senior citizens to a much smaller home, they rented 3 spacious storage sheds which they rarely entered, yet quickly filled their new home to the brim including lining the staircases with books and other objects, covering the floors with papers, and rendering the dining room table unusable with stuff. By the time they died in their early eighties, the papers downstairs in the rooms you could enter were about a foot deep covering the entire floor space. Floor was not visible. This made ambulation unsafe and eventually prompted my father to rent a room in another living space. Depression was certainly a co-morbidity with my mother from early on, and eventually with both parents. My mother suffered with trauma of several sorts as a child, including having much of what she owned sold out from under her. Hoarding was part of her response. It doesn't age well, and neither does depression. The combination is ugly. Cleaning out their home when they passed was a nightmare. They could not bring themselves to accept our help when they were living.

As a homeowner myself, I have experienced the shame and overwhelm as a hostess whenever I did let people other than family members into my home. My husband did not understand what my problem was, quite literally. It was a source of friction between us. One day I returned from work to discover that, while I was out, he had called 1-800-GOT JUNK and had them throw out a lot of stuff from our garage. Much of it was mine. He did not tell me until they had already come and gone, nor did he ask my agreement. He was so proud. I was horrified. The sense of betrayal was sharp. If anything, it made me hold on to our possessions more tightly. Our daughters were apologetic to friends who came over, if they weren't too embarrassed to have them over at all. It was painful to see how much more relaxed they were at their paternal grandparents' much more sparsely furnished home. I knew I wanted to do better. But I didn't know ***how.*** Books on clutter might help me to organize pockets of stuff like paperwork or craft supplies, but they didn't help either with the impulse to hoard or with the impulse to gather MORE of whatever I was collecting.

I have found the most helpful resources by far to be people who understand that hoarding disorder is often rooted in trauma and have personal and/or professional experience assisting those who are afflicted with it. The **Buried in Treasures** book by Tolin and Frost and the workshops by Lee Shuer and Rebecca Belofsky have been enormously helpful to me. Not only did they offer practical suggestions for understanding and addressing hoarding disorder, but offered peer support which has been ongoing in a small group format for several years beyond the course. I am able to afford individual therapy which gives me insight into the particular role that trauma and depression may play in hoarding disorder for me in particular. Many cannot. Access to good mental health care is essential. Exploring hoarding phenomena with fellow travelers is very healing as well. I have made enormous strides in reducing the volume of stuff in our home. We have gotten creative in how and where we share donations so there is as little

waste as possible. This is often a sticking point for people who hoard. My husband has learned that his getting rid of HIS stuff is helpful, but his getting rid of MY stuff is not. However, he is wonderful about helping me get things out of the house once I have decided to let go of them and making extra runs to Goodwill or other collection centers! This kind of help in general is great for those who hoard: extra hands to help move what they have already decided to share or toss, available bags, bins and dumpsters to hold what is kept or discarded, access to a vehicle to help get rid of whatever goes out. Once our house started to improve, our daughters both came home for Christmas, something they had not done in several years. I wept for joy.

In sum, the problem of Hoarding Disorder itself is as varied as the people who wrestle with it. Having said that, there are some universal truths:

1. It is helpful to understand that **this is a genuine challenge** for the individual who suffers from it, and they may be as baffled by it as you are.

2. Throwing some things out that **you** think should go if they are **not your things** can be very **destructive**.

3. It is essential to treat the person who has HD with **compassion and dignity**.

4. **Peer support** can be immensely helpful.

5. While it is easy to be impatient, expecting a **quick fix is not realistic** for many of these cases. Providing trained support regularly and consistently over time will be key.

6. When a person who hoards is open to getting rid of some things whether by choice or under threat of eviction, having affordable **physical help** can be essential.

Some states such as California have excellent resources which are well-catalogued, easily accessible, and even free to in-state residents. Others have little or nothing. I am hopeful that efforts such as yours will help us move toward better resources being accessible for a greater number of people.

Statement from James C. Appleby, Chief Executive Officer, Gerontological Society of America

GERONTOLOGICAL SOCIETY OF AMERICA®

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www.geron.org

Meaningful Lives As We Age

April 15, 2024

Senator Bob Casey
Chairman, Senate Special Committee on Aging
G16 Dirksen Senate Office Building
Washington, DC 20510

Senator Mike Braun
Ranking Member, Senate Special Committee on Aging
628 Hart Senate Office Building
Washington, DC 20510

RE: **Request for Information regarding the impact of Hoarding Disorder on older adults**

Submitted electronically via hoardingdisorder@aging.senate.gov

Dear Chairman Casey and Ranking Member Braun,

The Gerontological Society of America (GSA) appreciates the opportunity to provide comments to the **Request for Information (RFI) regarding the impact of Hoarding Disorder (HD) on older adults.**

GSA honors aging across the lifespan and is the nation's oldest and largest interdisciplinary organization devoted to research, education, and practice in the field of aging. The principal mission of the Society — and its 5,400+ members — is to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy. We encourage interdisciplinary research collaboration and communication. We routinely convene communities of interest to discuss issues of importance and make recommendations to address the specific needs of older adults.

- **How has Hoarding Disorder impacted your community, particularly older adults and people with disabilities?**

Hoarding Disorder (HD) is a chronic condition associated with moderate to severe impairment in health and functioning and has impacted the lives of older adults and their caregivers. Significant health, safety, and functional consequences have been found in older adults meeting criteria for Hoarding Disorder, compulsive hoarding, and hoarding symptoms.

Research conducted on this topic and published in The Gerontological Society of America Journals, including a study on cognitive remediation treatment components for hoarding in older adults.

According to Mary E. Dozier, PhD, an Assistant Professor in the Department of Psychology at Mississippi State University and active GSA member, Hoarding Disorder in older adults has been underappreciated historically, in part due to widespread stigma. **One in three older adults with Hoarding Disorder have co-morbid major depressive disorder, and the majority exhibit maladaptive personality traits as well, Dr. Dozier notes.**

GSA
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Meaningful Lives As We Age

Dr. Dozier published several articles in GSA's Journals. Additionally, she serves as a convener of GSA's Mental Health Practice and Aging Interest Group, an interdisciplinary community of researchers and clinicians interested in mental health interventions for older adults.

"Clinicians who work closely with older adults, and especially those who work in home-based settings, regularly encounter hoarding as a barrier to proper health," Dr. Dozier notes. "**Hoarding [Disorder] is linked to increased medical issues both due to the increased incidence of health hazards such as mold or insect infestations, as well as decreased ability to use rooms in the home such as the kitchen or bathroom**." Furthermore, Dr. Dozier notes that Hoarding Disorder issues are not regularly identified by clinicians and create interpersonal conflict with loved ones leading to increased social isolation and loneliness.

- **How has your organization responded to Hoarding Disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?**

GSA publishes research in our journals and disseminates this evidence through several mechanisms including our Annual Scientific Meeting. GSA's Mental Health Practice and Aging Interest Group continues to amplify research in this area including with community-based partners.

The largest challenge is funding for research, development, and implementation of evidenced-based treatments and intervention strategies.

- **How can the federal government help your organization assist older adults and others with Hoarding Disorder?**

GSA strongly urges policymakers to prioritize funding for research to develop evidence-based interventions and treatment models that are translated into practice for people with Hoarding Disorder.

Thank you for the opportunity to provide information regarding Hoarding Disorder. If you have any questions, please contact Patricia D'Antonio, Vice President of Policy and Professional Affairs at [redacted]

We look forward to continuing to work with you on this issue.

Sincerely,

James C. Appleby, BSPharm, MPH, ScD (Hon)
Chief Executive Officer

Statement from Kim Cox, President-Elect, The Institute for Challenging Disorganization

2005 Palmer Ave. #1068, Larchmont, NY 10538, (800) 674-7818, icd@challengingdisorganization.org

April 15, 2024

To: The Honorable Members of the United States Senate Special Committee on Aging

From: Kim Cox, MA, President-Elect, The Institute for Challenging Disorganization®

Subject: Insights and Recommendations on Hoarding Disorder and Older Adults

The Institute for Challenging Disorganization® extends our gratitude to your committee for prioritizing the exploration of Hoarding Disorder (HD) and its profound impact on communities, especially among older adults and individuals with disabilities.

Chronic Disorganization (CD) is a concept that was created by our founder, professional organizer, pioneer, and industry thought leader, Judith Kolberg[1] in the early 1990's. The concept was embraced globally, and the National Study Group of Chronic Disorganization® (NSGCD®) was born. Later changing its name to The Institute for Challenging Disorganization® (ICD®), the 501(c)(3) nonprofit has evolved into a global leader in the provision of educational resources and strategies for addressing CD, with over 400 subscribers (81% are in the U.S.[2]).

The ICD mission, to provide education, research, and strategies to benefit people challenged by CD, is carried out through a globally recognized credentialing program, the creation of educational materials for allied professionals and professional organizers, and the fostering of a collaborative professional network.

CD persists over a long period of time, frequently undermines the quality of life, and recurs despite repeated self-help attempts. CD often coexists with brain-based challenges such as HD and hoarding behaviors, Attention Deficit Hyperactivity Disorder, Anxiety and Depression.

The ICD and our sister organization, the National Association of Productivity & Organizing Professionals® (NAPO®), are in alignment in our devotion to delivering quality education to professional organizers and coaches who service people who are impacted by HD and are especially attuned to the needs of older adults. Many subscribers/members invest in both organizations for education and professional fellowship.

ICD Education, Research, Strategies
For 28 years, the ICD has hosted an annual conference open to both subscribers and the general public.

[1] https://www.judithkolberg.com/
[2] https://icdorg.memberclicks.net

Our community is made up of Professional Organizers, Productivity Specialists, and other related professionals who want to know why our clients are affected by chronic disorganization. We understand that the brain has a lot to do with a client's ability to be organized and to maintain organizational and productivity systems. Brain-based challenges, whether congenital or acquired, directly impact organizational skills. Because of these brain differences, we seek education from professionals in the medical, educational and neuroscience communities. The training and resources available to our subscribers make us better equipped to help clients affected by chronic disorganization.

We strive to provide our clients with

- *strategies for overcoming their brains' natural tendencies.*
- *access to the latest research, techniques and best practices.*

We are passionate about serving people living with chronic disorganization, and value collaborating with counselors, coaches, therapists, researchers, and doctors. [as stated on the ICD website[3]]

ICD Insights on Hoarding Disorder

- Our subscribers report a growing need for their services, but consumers are faced with a lack of funding and resources.
- Private health insurance companies will not accept billable hours from professional organizers.
- There is a demand for more local Hoarding Task Forces to address the fragmented systems currently in place.
- Very few of our subscribers who participate on a local task force are compensated. While they may have more education and expertise in the field, they lack the authorization to coordinate resources.
- The scarcity of affordable housing, limited mental health resources experienced in HD, and a lack of supportive social systems exacerbate the struggles faced by individuals with HD.
- The absence of uniform protocols among professionals encountering HD contributes to the complexity of managing this disorder.

Influence on the ICD Education and Research

The rising prevalence of HD cases has steered the ICD towards the development of specialized certification programs in HD, emphasizing a heightened interest and need for qualified professionals. Our role in educating and destigmatizing HD extends to a need for the increasing importance of informed and compassionate interventions.

Certificates ICD offers include the following:

- Level I (6 hours each):
    - Foundation Certificate in Chronic Disorganization (required for all specialist certificates)
    - Certificate of Study in ADHD
    - Certificate of Study in Understanding the Needs of the Aging Client
    - Certificate of Study in Understanding Hoarding Behavior

[3] ICD website What is ICD?: https://www.challengingdisorganization.org/what-is-icd

- Level II (12 hours each):
    - Chronic Disorganization Specialist® Certificate
    - ADHD Organizing Specialist Certificate
    - Aging Specialist Certificate
    - Hoarding Specialist Certificate
    - Time Management and Productivity Specialist Certificate
- Level III (17-20 months)
    - Certified Professional Organizer in Chronic Disorganization (CPO-CD)

The ICD has responded proactively through the establishment of a comprehensive education platform, certification programs focusing on vulnerabilities in the elderly, specific HD expertise, and the provision of valuable cross-discipline assessment tools such as the Clutter-Hoarding Scale®[4] and the Clutter Quality of Life Scale®[5].

The ICD Research Committee actively works to identify researchers around the world in areas such as HD, neurodiversity, ADHD, factors of aging and all topics related to CD such as excessive clutter and time management issues, and co-occurring conditions related to extreme clutter and procrastination, as well as therapeutic topics such as compassionate mind training. The research committee also:

- Cultivates collaborations with new and veteran researchers related to topics of disorganization.
- Identifies and shares ongoing research with our current subscribers and allied professionals.
- Offers grants for research, at the master's and doctoral levels, to encourage an interest in researching areas related to CD.
- Stays active identifying research to share with our subscribers through ICD classes, white papers, subscriber newsletter, and online resources.
- Features researchers at our annual conference.

Challenges

Despite our efforts, the ICD faces obstacles such as limited recognition of the front-line role of professional organizers in mitigating CD and HD, resource constraints, and insufficient funding for broader engagement, education and service delivery. These challenges highlight the necessity for enhanced support and acknowledgment from both governmental and private sectors.

Recommendations for Federal Assistance

To amplify the effectiveness of organizations like the ICD in combating HD, especially among vulnerable populations, we suggest the following actions by the federal government that would make a significant difference in the lives of millions affected by hoarding behaviors.

- Widespread distribution of the Clutter-Hoarding Scale , the Quality of Life Scale, and the CD Fact Sheets[6] that are translated into eight languages to enhance awareness and understanding

[4] https://www.challengingdisorganization.org/clutter-hoarding-scale
[5] https://www.challengingdisorganization.org/clutter-quality-of-life-scale
[6] https://www.challengingdisorganization.org/icd-fact-sheets

across governmental agencies. Imagine the impact of this education in even the single most populated, ethnically diverse county in the United States: Queens, NY.

- Implementation of public medical insurance coverage codes that recognize the contributions of qualified and trained professional organizers, coaches, and other allied health professionals in the treatment and remediation of HD.
- Establishment of training and education programs for agencies, first responders, and mental health professionals to ensure a unified and informed approach to HD.
- Allocation of funds specifically for research in the field of HD and hoarding behaviors to support evidence-based practices and interventions provided by qualified professional organizers, coaches, and other allied health professionals.

Conclusion

The ICD is poised to continue its mission of providing education, fostering research, and supporting individuals affected by Chronic Disorganization and Hoarding Disorder and HD behaviors. With the collaborative support of the federal government, we can extend our reach and efficacy, making significant strides in addressing the challenges posed by HD.

We welcome the opportunity to continue the conversation and explore how the ICD can be of service to the Special Committee on Aging and those who are seeking more understanding and resources to help those who are impacted by HD.

Please contact me at [redacted] if you have any questions.

Sincerely,

Kim Cox, MA, ICD President-Elect

on behalf of

The ICD Board of Directors

Contributions by Judith Kolberg, Industry Thought Leader (ICD/NAPO), Melissa Hladek, CSA®, CPO-CD®, CPO® (ICD/NAPO), and Leslie Hatch Gail, Ph.D. (NAPO)

Statement from Georgia Goodman, Director, Medicaid Policy, LeadingAge

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.

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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.

Tennant 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 serivces. If you have additional questions, please don't hesitate to reach out.

Sincerely,

Georgia Goodman
Director, Medicaid Policy
LeadingAge
[redacted]

Statement from the National Adult Protective Services Association

NATIONAL ADULT PROTECTIVE SERVICES ASSOCIATION

Senate Special Committee on Aging
United States Senate
Washington, DC 20510

April 15, 2024

Chair Casey, Ranking Member Braun, and Members of the Committee,

The National Adult Protective Services Association (NAPSA) is pleased to take this opportunity to provide feedback to the Committee on hoarding disorder and its impact on the community, specifically adult protective services. We applaud your focus on this issue and its impact on the community. NAPSA represents the nation's state and local APS programs. APS is the nation's only system of statutorily authorized civil programs to investigate and respond to vulnerable adult abuse, neglect, self-neglect, and exploitation. Over 90 percent of states serve all persons with significant disabilities who are age 18 and older; while several serve only persons 60 or 65 and older. All APS programs investigate abuse in home settings, where 90 percent of older persons live, nearly all have jurisdiction in assisted living facilities, but only about half are authorized under state law to investigate in nursing facilities.

APS programs most frequently encounter hoarding disorder as part of self-neglect cases. As noted in the National Adult Maltreatment Reporting System (NAMRS), self-neglect is "a person's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including … hoarding." While NAMRS does not currently collect statistics on hoarding, the report does note that self-neglect is the most frequent type of case with clients often returning to APS[1]. These clients frequently-require in-home assistance, case management, legal services, and housing assistance among other supports[2].

Hoarding disorder impacts the community through increased need for services and costs of support. In particular, hoarding can become a neighborhood or building-wide concern in regard to building structural damage or rodent infestation. Services and resources are often in short supply, particularly mental health support. Hoarding cases can also bring to light misunderstandings between partners and a need to educate partners on APS' role in the situation, including the inability to evict an individual.

Hoarding impacts APS organizations through limited resources. Cases involving hoarding disorder often cost an exorbitant amount to both clean the home and get assistance for the client. In a NAPSA survey one state noted that hoarding services can cost up to $5,000 for each situation. And these are often repeat clients due to the challenging nature of the disorder. Further, cleaning of the residence is often a requirement before bringing in home health aides or other support. Legal representation may be needed if an individual lacks capacity. An Ohio worker noted cases involving "situational hoarders" after the COVID-19 public health emergency. These were individuals who may not have exhibited hoarding

[1] McGee, L. & Urban, K. (2022). Adult Maltreatment Data Report 2021. Submitted to the Administration for Community Living, U.S. Department of Health and Human Services. https://pstrapiubntstorage.blob.core.windows.net/strapib/assets/2021%20Adult%20Maltreatment%20Report_Ready%20for%20508_ADA.pdf

[2] ADvancing States (2024). Adult Protective Services in 2022: Responding to Evolving Needs in a Changing Environment. https://www.advancingstates.org/sites/nasuad/files/APS%20Report%201.11.24%20Final.pdf

behavior previously but were not able to have cleaning support due to pandemic restrictions leading to a hoarding situation. While there are no statistics on this phenomenon it is of potential impact.

APS providers have responded to hoarding disorder through partnerships and services such as deep cleaning and case management. Many APS programs are part of hoarding task forces or other related multi-disciplinary teams to leverage a range of services. Most importantly, recent federal funding has allowed APS programs to invest in services to address hoarding cases. Deep cleaning was one of the top uses of Coronavirus Response and Relief Supplemental Appropriations Act and the American Rescue Plan Act. Other top service uses assisted with helping clients to live independently in their homes. A top challenge to continuing to address these issues is funding. This significant appropriation has not been continued; rather, it has dropped significantly. Without this support many services will be discontinued.

The federal government can help assist APS programs in addressing hoarding behaviors in a number of ways. Support from Congress could make a significant difference in the lives of APS clients. We recommend:

- Amend the Older Americans Act to prioritize services to adults experiencing abuse, neglect, self-neglect, and exploitation, particularly those involved with APS. Clients facing hoarding disorder require support beyond just deep cleaning to live independently and maintain a safe home. Being put at the end of the waiting list prevents individuals from receiving services that may be critical in preventing reoccurrence.
- Promote and build connections with mental health at the federal, state, and local levels. APS programs consistently report that mental health support is under resourced or not available at all. Mental health support is crucial in addressing hoarding behaviors and avoiding a recurrence of the situation. Ongoing support is needed to avoid further clean outs and traumatization of the individual. This could include funding to APS and mental health organizations to build pilots and demonstrations.
- Increase federal funding to Adult Protective Services. Increasing resources for APS is ultimately the only way to support front line staff in these issues. One APS administrator noted that extra funding and supports saves money when Medicaid does not have to pay for facility level care that is not needed. However, an appropriation of $15 million is not suffcient and is an affront to the demanding work of APS agencies. NAPSA is calling for at least $100 million in annual funding for APS programs and more is needed.

As noted, self-neglect cases, particularly those involving hoarding disorder, are some of the most challenging cases encountered by APS workers. Front-line staff are dedicated to supporting clients to the fullest extent possible, but they need the support of Congress. We appreciate the interest of the Senate Special Committee on Aging regarding this issue and encourage further focus on the successes and challenges of adult protective services programs.

Sincerely,

Jennifer Spoeri
Executive Director
National Adult Protective Services Association

William Benson
National Policy Advisor
National Adult Protective Services Association

Statement from Barbara Bedney, Chief of Programs, National Association of Social Workers

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NASW
National Association of Social Workers

April 15, 2024

Senator Robert P. Casey, Jr., Chairperson
Senator Mike Braun, Ranking Member
U.S. Senate Special Committee on Aging
Washington, DC 20510-5364

Submitted electronically to HoardingDisorder@aging.senate.gov

Re: Request for information (RFI) regarding the impact of hoarding disorder (issued March 19, 2024)

Dear Senator Casey and Senator Braun:

On behalf of the National Association of Social Workers (NASW), I am responding to Senate Aging Committee's RFI regarding the impact of hoarding disorder (issued March 19, 2024). NASW concurs with the Senate Special Committee on Aging (hereafter, "the committee") that hoarding is a significant problem in the United States, and we appreciate the committee's efforts to understand and address it.

Founded in 1955, NASW is the largest membership organization of professional social workers in the United States, representing more than 110,000 social workers. We work to enhance the professional growth and development of our members, to create and maintain professional practice standards, and to advance sound social policies.

Social workers work with and on behalf of older adults in numerous settings, including across the spectrums of health, housing, mental health, and long-term services and supports. As such, they are well positioned to identify and respond to hoarding behavior in older adults; clinical social workers, in particular, are qualified to diagnose and provide mental health treatment for hoarding disorder. Thus, NASW has disseminated the RFI widely, encouraging gerontological social workers to offer their input to the committee. Our senior practice associate for aging, Chris Herman, also appreciated the opportunity to talk with committee staff Doug Hartman a few weeks ago and to direct Doug to social workers who have professional expertise in addressing hoarding. We hope these actions will generate useful information for the committee.

Recognizing the significance of hoarding disorder, NASW offers the following resources to social workers:

- *Understanding Hoarding: A Guide for Clinicians* (live program only; August 9, 2024)—Webinar to be presented for the NASW Iowa Chapter by social worker Susan Dannen, co-owner of River Roots Mental Health & Wellness Center (program description)

- *Thinking Outside the Box: Novel Delivery Methods for Treating Hoarding* (2013)—Webinar presented for the NASW Massachusetts Chapter by Dr. Jordana Muroff, now associate professor and chair of the Clinical Practice Department at the Boston University School of Social Work (available on demand)
- *Hoarding: Insights and Innovations for Social Workers* (original date not listed)—Webinar presented for NASW Specialty Practice Section members by social worker Christa Tipton, longtime cochair of the NASW California Chapter Technology Committee and then senior social worker with Adult Protective Services and a member of the Orange County Hoarding Task Force (available on demand)
- *Compulsive Hoarding* (2013)—Webinar presented for the NASW Massachusetts Chapter by Dr. Randy O. Frost, now professor emeritus of psychology at Smith College, and social worker Patricia C. Carleton, then a member of the chapter staff (available on demand)
- *Cluttered Lives, Empty Souls: Compulsive Theft, Spending & Hoarding* (2014)—Breakout session presented at the NASW national conference by social worker and attorney Terrence Shulman, founder and director of the Shulman Center for Compulsive Theft, Spending & Hoarding (slides)
- *Older Adults and Compulsive Hoarding: When It's More than Clutter* (2010)—Webinar presented for NASW Specialty Practice Section members by Dr. Barbara Soniat, then associate professor of social work and director of the Center on Global Aging at the National Catholic School of Social Service (no longer available)
- *Empowering Social Work with Vulnerable Older Adults* (2010)—Book coauthored by Dr. Soniat and Monica Melady Micklos and copublished by NASW Press (information); includes a chapter on older adults who hoard

Based on our understanding of hoarding and the resources described above, NASW encourages the federal government to consider the following strategies to assist older adults and others living with hoarding disorder:

- Hold Congressional hearings on hoarding.
- Conduct research, such as under the auspices of ASPE, on hoarding disorder.
- Devote attention to the link between hoarding and elder abuse within the Elder Justice Coordinating Council.
- Encourage the development of action plans within ACL, CMS, HRSA, HUD, SAMHSA, and the VA.
- Foster cross-agency collaboration among ACL, CMS, HRSA, HUD, SAMHSA, and the VA.
- Develop and promote both consumer and professional education on hoarding. Ideally, such development and dissemination would reflect collaboration among ACL, CMS, HRSA, HUD, SAMHSA, and the VA.

Thank you for your consideration of NASW's comments. Please contact me at [redacted] if you would like additional information or have any questions.

Sincerely,

Barbara Bedney, PHD, MSW

Barbara Bedney, PhD, MSW
Chief of Programs

Statement from Sean Patrick Carroll, Director Government Relations, National Fallen Firefighters Foundation

April 11, 2024

The Honorable Bob Casey
Chairman
United States Senate Special Committee on Aging
G16 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mike Braun
Ranking Member
United States Senate Special Committee on Aging
628 Hart Senate Office Building
Washington, DC 20510

Dear Senator Casey and Senator Braun,

On behalf of the National Fallen Firefighters Foundation (NFFF), please find below our response to your March 19, 2024, Request for Information regarding hoarding disorder. NFFF worked closely with Ryan Pennington, a fire captain from Charleston, WV, who has 12 years of experience researching and teaching about the effects of hoarding as it relates to fire and emergency response. Thank you for the opportunity to address this important issue. We hope you find our response informative.

How has Hoarding Disorder impacted your community, particularly in older adults and people with disabilities?

The fire service is seeing an increasing number of cases of hoarding calls for service including EMS, structural fires, and assistance in various emergencies. This directly impacts the responding providers in different ways, including reducing the ability to treat medical emergencies and impeding interior fire suppression.

These challenges can delay needed emergency medical care and reduce the chances of a rescue from a structural fire. While the level of hoarding varies, it is often found to severely reduce the access and available living spaces within a property. With this limited access, our elderly and disabled community members are not receiving the needed daily care and are often unable to obtain food.

How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Emergency medical responses in hoarding conditions takes on aspects of a

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410.721.6212 *Phone* ♦ 410.721.6213 *Fax*

www.FireHero.org ♦ FireHero@FireHero.org

technical rescue. The limited access and collapse potential require extra resources and often specialized rescue personnel to stabilize stacks of content and dilapidated structures.

Accessing the patient through the small passageways created by the large amounts of debris requires the patient to be carried out by hand due to the inability to bring in the stretcher or stair chair. This can make an injury or illness worse and puts emergency response personnel at a higher risk for injury.

Structure fires with hoarding conditions are among the most dangerous conditions the fire service can encounter. Access issues, fires at the bottom of the debris piles, overloaded structures, and the inability to assess the building due to exterior clutter are just a few examples of the extreme hazards faced in these situations.

These fires require an increased number of firefighters, longer working periods, and often demolition of the property for complete extinguishment. Increased risk of injury from disorientation and falling debris amplify the dangers associated with a potential search and rescue of trapped occupants.

How has your organization responded to hoarding disorder, including through establishing new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

Tactics for addressing hoarding disorder have received limited attention in the fire service, although some departments are beginning to develop operational considerations. Many departments are starting to pre-fire plan known hoarding locations, adjusting the number of personnel on the scene of the emergency, and working with fire marshals to enforce building codes. Some areas are further along in these adjustments than others.

How can the federal government help your organization assist older adults and others with hoarding disorder?

It is critical we begin tracking the number of structure fires involving some level of hoarding. Current data is largely compiled from media reports and hearsay. As the United States Fire Administration (USFA) continues to upgrade the national reporting system, steps should be taken to identify clutter on a set scale to allow the fire service to identify just how big of an issue this has become.

Additionally, Congress should provide funding for the establishment and delivery of a nationwide educational program for fire service personnel through USFA's National Fire Academy. There are very few educators teaching the needed adjustment for responses in cluttered conditions. Through virtual and in-person learning, we can train our firefighters and emergency medical providers on best practices for responding to emergencies in hoarding conditions.

Finally, the federal government should establish an aggressive education system for homeowners. It is important for them to understand that Compulsive Hoarding Disorder is just that, a mental disorder. The need for homeowner education is essential for reducing the number of hoarding cases we will see in the future.

Should you have any questions, or if we can be of further assistance, I can be reached at [redacted]. Best wishes for your continued success and safety.

Sincerely,

Sean Patrick Carroll
Director Government Relations
National Fallen Firefighters Foundation

Statement from Jan M. Enders, Benefits Counselor II, Area Agency on Aging for the Heart of Texas (HOTCOG)

Submitted on April 9, 2024

Mr. Doug Hartman:

I am writing in response to a request for written responses regarding hoarding:

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Answer: Hoarding is prevalent among older adults in as much as no one wants to address hoarding. With the assistance of Family and Protective Services, Area Agency on Aging, other partners presented a Hoarding conference and addressed animal hoarding, clothing hoarding, appliance hoarding, paper, garbage, etc. There are very few agencies who will help clean up a hoarder's home, apt. We had to partner with a home health agency who volunteered to clean up a home. Costs are prohibitive. We started our conference with psychological assistance and progressed throughout the day to animal hoarding. Usually, there is an underlying psychological disturbance that triggers hoarding. Families choose not to get involved and the older person is too weak or frail to address all the issues. Psychological assistance is sometimes prohibitive in cost. We were quoted $4000 to address the person first and hoarding second.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Answer: When hoarding occurs, no one wants to go into the home to assist an individual with personal care, meal prep, etc. Often rooms are so full of items usually packed through to the ceiling, that the Person's ability to complete activities of daily living is hampered. Agencies cannot help people with rooms so full of debris. Houses, apartments need to be cleared out before services can be provided. Thus the conundrum.

3. How has your organization responded to hoarding disorder, including through establish any new or unique initiatives? What, if any challenges has your organization faced while implementing that response?

Answer: We have tried to partner with Adult Protective Services, home health agencies. Cost of removing debris is sometimes prohibitive. Our agency does not have the funding to address hoarding on a large scale. We work within the communities to rally agencies to assist. Health Department, City attorneys, etc. Very frustrating.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

Answer: Have more federal programs addressing hoarding. We used the free advice and counsel of the television show on hoarding to guide us to what would have the best impact for the community.

Additional funding for clean-up. What constitutes hoarding? More code enforcement is required. Sometimes city attorneys are unwilling to address hoarding as it becomes a massive undertaking. We had a woman with 5 house filled to the brim with debris. Eventually, for tax collection, the homes were cleaned and city tore down homes to pay past due collections. Work with city managers on hoarding to see how prevalent it is.

We are participating with Adult Protective Services in promoting awareness of hoarding and it is a top priority as we reformulate the APS board. Some homes are health hazards and need condemnation as they are a threat to public health. We will continue to address hoarding by education and working together as a community to assist people in need.

Thank you for tackling this difficult situation.

Respectfully yours,

Jan M. Enders

Jan M. Enders, M.S.G., Gerontologist
Benefits Counselor II, HICAP/SHIP
Manager, Programs, Training, Development
Area Agency on Aging of the Heart of Texas, HOTCOG
1514 S. New Road
Waco, TX 76711

Senate Special Committee on Aging RFI on Hoarding

Statement from Allegheny County Department of Human Services

Pittsburgh, Pennsylvania 15222

April 14, 2024

1. **How has hoarding disorder impacted your community, particularly older adults and people with disabilities?**

As the Allegheny County Department of Human Services (ACDHS), we receive numerous calls every year from individuals, family members, first responders, code enforcement, and concerned neighbors regarding people living in hoarded conditions. These conditions also affect nearby community members. Neighbors are concerned about their property values, rodents and other critters when living next to a hoarded property.

Family members and even those living in hoarded conditions are oftentimes overwhelmed by the condition of their home and cannot pay for the cost of a clean out with or without biohazardous waste present. Homes that are at a level 5 hoarding rating require extensive repairs that are very costly. We face many challenges in addressing these concerns including addressing the concerns of the person calling while also respecting the rights of the person who is hoarding. Additionally, first responders often have difficulty accessing people in need of their services and put their own lives at risk when trying to gain entry to a home that is extremely cluttered.

The cause of hoarding in older adults and people with disabilities has a variety of underlying causes and may be due to lack of independent living skills, lack of affordability of cleaning supplies, symptoms of a mental illness (either hoarding disorder or another mental health diagnosis), as the result of physical health problems, a trauma history, and more. A survey of providers conducted by the Allegheny County Area Agency on Aging identified the following impacts of hoarding: unsafe/unsanitary housing conditions, legal recourse resulting in the loss of one's home and resulting homelessness, and financial burden (derived from when individuals refuse

services and receive a citation for code violations or health department violations which results in the person accumulating fines).

Hoarding creates safety hazards both for individuals engaging in hoarding behaviors and for first responders. It reduces first responders' ability to access individuals in crisis. Police departments, fire departments and code enforcement officers have contacted ACDHS to ask for assistance with addressing hoarded homes. Fire departments have found it extremely difficult to extinguish house fires where hoarding is present and have sustained injuries while trying to gain access to people trapped in burning homes. They have also found it difficult to rescue occupants of homes where hoarding is present. Paramedics have reported being unable to gain access to people in need of their services, due to extensive clutter and no way of getting through the home. Police officers struggle to address complaints by community members who are impacted by the hoarding of their neighbors. Neighbors of hoarded properties call to complain about vermin, infestations, and debris that is affecting the caller's property value.

Additionally, hoarding contributes to homelessness. Older adults and individuals with disabilities have been evicted from their homes as a result of the poor conditions of their homes. They have received legal citations and fines, and their homes have been condemned. When natural or man-made disasters affect people who are living in hoarded conditions, the severe clutter existing pre-disaster oftentimes prevents the person impacted by the disaster from being able to complete the steps necessary to remediate the damage caused by the disaster. As a result, the person must either continue to live in deplorable conditions or become homeless.

In Allegheny County, the Homeless Services Program often encounters individuals as they are suffering the consequences of hoarding behaviors. These consequences include eviction and then subsequent street homelessness or sheltered homelessness. Once an individual has an eviction on their record, housing pathways become narrower.

The complex nature of hoarding makes it extremely difficult to address because it requires identifying the underlying cause of the hoarded conditions to properly address without further traumatizing the individual. It is also very costly to conduct cleanouts as the conditions of the home and property worsen. Housekeeping and homemaker service providers will not work with a person who has extensive clutter in their home until after the clutter is removed. They will help to maintain the home moving forward, however. If there is an infestation, the infestation must be resolved prior to in-home services beginning; although, exterminators require the home to be free of clutter, before they can treat the home for infestations. This creates a vicious cycle that often results in the person either getting no help or being permanently removed from their home and the home being abandoned and eventually condemned.

There is no single entity that can address the complex needs of individuals experiencing hoarding disorder. When individuals reach out for help with addressing this issue, they are often bounced from one program or service to another, due to the lack of resources available to address the treatment aspect of the disorder and the lack of affordable services to help with cleanouts.

One individual who was just under 55 years of age was being sued by the township in which he lived, due to the severe hoarded status of his home. A social worker trying to assist him found it very difficult to identify services that specialize in working with individuals who hoard in Allegheny County. If they are located and accept a person's health insurance, there is oftentimes a lengthy waitlist for services. On the International OCD Foundation's website, for instance, there are three licensed counselors, one psychiatrist, one psychologist, one marriage and family therapist, one intensive treatment program for adults who hoard and one pediatric intensive treatment program within 25 miles of Pittsburgh, PA.

Elderly and individuals with disabilities have been evicted from their homes as a result of the poor conditions of their homes. They have received legal citations and fines, and their homes have been condemned. One provider shared the following comments:

-“Infestations of pests are not able to be remedied, resulting in having to dispose of everything”
-“Clients are too old to move their things, and we cannot find help”
-“Trip and fall hazards”

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

The mission of the Allegheny County Department of Human Services (ACDHS) is to create an accessible, culturally competent, integrated and comprehensive human services system that ensures individually tailored, seamless and holistic services to Allegheny County residents, in particular, the county’s vulnerable populations.

Our department operates many different funding streams with a variety of eligibility requirements. Hoarding is complex and can impact people of differing ages, abilities, socioeconomic statuses, races and educational levels. It does not discriminate. Because there are various eligibility requirements and allowable expenses for each funding stream, addressing hoarding disorder must be done through a multi-faceted approach with funding coming from multiple avenues. The human services system alone cannot address hoarded conditions. Addressing hoarding disorder oftentimes requires collaboration between older adult services, behavioral health services, physical health services, homelessness prevention services, services for children and families, and/or intellectual and developmental disability services, as well as the health department, animal control, local code enforcement, law enforcement and magisterial district offices.

Departments within County government, and program offices within departments, often operate independently of one another. Separate funding streams and organizations in combination with the complexities of addressing hoarding disorder which stems from multiple underlying causes, each requiring various types of collaboration of multiple public, private and governmental entities makes it extremely difficult for ACDHS to achieve our mission of “individually tailored, seamless, and holistic services to Allegheny County residents…”

Homeless shelters are mostly congregate living environments and have very little flexibility in their ability to accommodate the ongoing accumulation of personal belongings. Individuals who struggle with hoarding behaviors are often exited from shelters due to rule violations around personal belongings. After suffering the trauma of being involuntarily exited from shelter, some individuals opt to not return to shelter and enjoy the person freedom that comes with living outdoors. In extreme cases, some individuals have accumulated so many belongings that public health officials enforce a clearing of an area, and the individual is forced to relocate and repeat the cycle.

Providers submitted the following comments to a survey distributed by the Area Agency on Aging:

- "It makes it harder to serve our clients"
- "Many patients have difficult navigating throughout their house and debriefing the things that they do not need"
- "It can be a significant barrier to hospital discharge/transition planning"
- "We are often unable to get someone the appropriate help because the person will not consent to a one time clean up due to the trauma and anxiety it causes."
- "Hoarding has posed an obstacle to replacing private lead service lines I homes where severe hoarding has taken place."
- "Can and has become in some instances a health hazard"
- "While I appreciate the fact that Hoarding now has a DMS, this creates an ever greater challenge for anyone working in affordable housing. All residents must maintain their housing in order to receive their subsidies and to maintain residency. If they do not, they will receive an eviction notice with a possible eviction. However, for those with a Hoarding diagnosis or condition, they now somehow become above the rules because they have a 'condition'. Their homes/apartments create fire hazards and safety hazards. There are pests, smells, mild, feces etc. Other tenants should not be subjected to that and no home or apartment should be destroyed in that manner. The legal system has made it difficult to issue lease warnings and eviction notices due to a person's

'disability'. While I appreciate that a hoarder has a mental health condition, this does not make them above following the rules like everyone else that lives in their environment."

- "Our mission is to assist residents to age gracefully at home. Untreated HD does not allow this. Community, government nor aging resources are adequate."
- "It makes it difficult for our patients to go to/from treatment"
- "Because we have few resources to make referrals to help people who are in a very unhealthy and unsafe environment"
- "There is no agency which will help with cleaning and family is not always available."
- -We spend unrestricted funds on total clean outs in the cases abovementioned [infestations of pests]"
- "We have to relocate elders to hotels to avoid homelessness in the cases abovementioned [infestations of pests]"

3a. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives?

Hoarding Task Force of Allegheny County (2012-2017)

The Hoarding Task Force of Allegheny County, facilitated by ACDHS, met regularly between 2012 and 2017. In 2017, ACDHS worked unsuccessfully to identify community providers who could begin leading the coordination and facilitation of the task force. The last meeting of the task force was in December of 2017.

In 2016, three workgroups were developed to create a resource guide, develop educational materials for specific audiences, and to conduct a Needs Assessment.

In the winter of 2017, the Hoarding Task Force of Allegheny County conducted a Needs Assessment to determine the extent of the problem in the county and to develop strategies to address the findings. Five key conclusions recurred throughout the survey:

(1) A mixture of positive approach interventions is required to achieve successful outcomes in a hoarding situation;

(2) There is a need to increase the number of therapists/professionals trained to treat hoarding disorder;

(3) There is a need to provide ongoing support services for individuals with a hoarding disorder, particularly in-home support;

(4) There is a need to increase the number of professional and community education and training activities related to hoarding disorder; and,

(5) Individuals with hoarding disorder do better when there is a support network of individuals with a hoarding disorder.

Hoarding Pilot Program (2016-2018)

ACDHS funded a pilot program through a provider agency to operate a hoarding hotline, provide information on available internal/external resources to all hoarding-related inquiries, connect to available services, and refer to or facilitate an in-home assessment and/or arrange for in-home clean-up services. The provider also hosted a book club and Declutter Group for people who wanted to address their hoarding behaviors but who may or may not have been active in the Hoarding Disorder Pilot Program. The funding was limited, and the number of people able to receive services at any given time was less than 20. People accepted into the program would remain in the program, on average, for 18 months, and they received help with cleanout as well as supportive counseling. The provider reported that they had a difficult time making progress, due to the high rate of appointment cancellation by participants. Individuals interested in participating in the program remained on the waitung list for approximately 12 months. The funding for this program was discontinued as of 12/31/18.

Streamlining Service Access

In Spring 2021, The Pittsburgh Department of Permits, Licenses, and Inspections (PLI contacted ACDHS asking ACDHS to play an active role in remediating hoarding behaviors when PLI encounters them at homes in the

community. This request stemmed from PLI receiving numerous complaints about hoarded properties within the City of Pittsburgh.

In response, ACDHS reviewed existing programs and interviewed providers to assess how ACDHS could address the request of Pittsburgh Department of Permits, Licenses, and Inspections (PLI) to help address hoarding concerns within the City of Pittsburgh. The recommendations were:
(1) develop capacity at United Way/211 to build out a hoarding services clearinghouse so 211 can serve as the County's central point of contact for questions from individuals and stakeholders about hoarding services and resources; and, (2) maintain and circulate (including via United Way) a comprehensive list of county resources for both individuals who hoard and hoarding stakeholders. An additional recommendation that came out of this research was to consider allocation of funds to existing service providers to assist with the cost of heavier clean-out services for extreme clutter for those individuals who qualify for human services and want to de-clutter their space but lack the resources and the means to clean out large messes.

ACDHS worked with 211 to create an internal flow process for 211 call center staff to use when responding to calls regarding hoarding situations. Once 211 call center staff were trained to take all calls regarding hoarding concerns, ACDHS program offices were informed of this new process and began to follow it whenever they would receive calls regarding hoarded properties. DHS program offices also notified contracted providers of the updated process. Additionally, the resource guide created by the former Hoarding Task Force of Allegheny County that had continued to be updated by a DHS OBH staff person was forwarded to 211 for reference and distributed to any individuals or providers seeking hoarding resources. Unfortunately, 211 has received very few calls related to hoarding concerns, and the callers have only been able to be provided information about hoarding support groups and hoarding counseling programs.

Mobile Psychiatric Rehabilitation and Mobile Mental Health services for people with a mental health diagnosis and Medicaid insurance are available, but staff often lack the education and training regarding hoarding disorder. Providers have indicated a willingness to provide services specifically for people with hoarding disorder, providing they receive sufficient training and funding to pay for cleanouts. In addition, these programs oftentimes experience staffing shortages that limit their capacity to serve. There is a Hoarding Disorder Group Therapy Program through one of the Office of Behavioral Health's (OBH) providers. It is only able to serve 6 people at a time, operates virtually and is a closed group.

Area Agency on Aging Initiatives

Area Agency on Aging (AAA) offers chore services through its OPTIONS program. However, the scope of that program is limited. Major clean outs and biohazardous waste removal are not able to be provided under these services. AAA has secured a small amount of funding to help seniors with cleanouts as well as referrals to appropriate mental health providers and follow up. AAA has contracted with a contractor to provide professional organization/clutter management services and moving assistance for those seniors who need to relocate to a safe and clutter-free environment. Additionally, AAA is hosting a training on hoarding for professionals in May of 2024.

Providers submitted the following comments to a survey distributed by the Area Agency on Aging:

- "We have tried to work with people on an individual basis to enable them to stay here instead of having to be evicted."
- "Our Field Liaisons will refer hoarding residents to 211, United Way, AAA."
- "I don't know of any organization response to HD."
- "Attempted to get help for individuals through agency on aging."
- "We have been searching for provides to assist older adults with hoarding issues. This is an ongoing initiative,"
- "Families can sometimes assist with clean up. Our organization has Service Coordination to provide home visits and chore schedules.

They provide positive reinforcement and reminders of consequences…"

- "Social work interventions, linking patients with community resources"
- "We have had a representative on the hoarding taskforce."
- "We have no initiatives around hoarding, but are trying to catch it early and be proactive. We have reduced caseloads for those who case manage people in PSH [Permanent Supported Housing] program in order that they can have more time to help clients prevent or deal with hoarding."

Homeless Services

Due to limited resources, Homeless Services has not responded well to this need. Street Outreach initiatives have assisted some individuals in surviving on the street while their hoarding disorder symptoms persist.

Forthcoming Improvements

In August of 2023, AC DHS revisited the issue of hoarding and its response. The question of who will assess and coordinate the response for hoarding situations that pose a safety concern still remains, and funding for cleanouts continues to be a challenge.

Currently, the Office of Behavioral Health has formed an internal task force to work on addressing hoarding conditions due to a mental illness. OBH is seeking providers who are interested in conducting assessments of individuals who want to address their hoarding disorder.

With respect to people living in hoarded conditions who have also been impacted by a natural or man-made disaster, DHS has asked VOAD partners if they are able to assist with cleanouts. Creative solutions to assist individuals living in hoarding conditions who have been impacted by disaster continue to be explored. ACDHS also participates in the PADHS Disability Integration & Access and Functional Needs work group focused on hoarding.

3b. What, if any, challenges has your organization faced while implementing that response?

There are two primary challenges in implementing a response to needs associated with hoarding. First is limited funding – both lack of funding for services and cleanout and stringent eligibility policies which only provide services to low-income individuals.

Cleanouts are very expensive, and the funding AAA has secured is very limited. Many of our providers are at maximum capacity and would require additional funding to pay for the expense of cleanouts. They often report the need for more specialized training on hoarding disorder and best practice interventions to be able to assist someone living in hoarded conditions.

Eligibility criteria and capacity have been great challenges within the behavioral health system. Hoarding disorder does not discriminate based on socioeconomic status. Programs within the behavioral health system that do assist individuals with hoarding disorder are only available to people who have Medicaid health insurance coverage, meaning more affluent individuals impacted by hoarding disorder do not qualify. Commercial insurance and Medicare plans do not pay for Mobile Psychiatric Rehabilitation services, Mobile Mental Health services or in-home therapy.

According to hoarding disorder experts, "it is recommended that treatment involve regular home visits and visits to settings where clients have difficulty controlling their acquiring. Behavioral Health Service Coordination (case management) does not permit billing for travel time (given the high cancellation rate of appointments, they would lose significant productivity) nor for providing a direct service. Therefore, service coordinators are not able to assist people with cleaning out and organizing their homes. If a therapist or trained clinician is unable to bill for time spent in travel or able to bill for therapeutic services occurring in a person's home, then they are not able to provide best practice interventions.

The second significant challenge we face is the lack of leadership and cohesion. There is currently no single entity conducting assessments on the intensity or root cause of hoarding to prioritize and connect people to the appropriate services. Due to the complex nature and impact of this condition, it is not obviously apparent which department should take on this responsibility: human services, health, homeless prevention, and so on.

Additionally, we struggle with considering the rights of people to live how they choose to live versus the rights of their neighbors impacted by the hoarded conditions next to which they are living and the willingness of individuals to accept support.

With respect to disaster response, there are VOAD partners who assist with muck outs and debris removal, but none has stated that they are able and willing to assist with cleanouts of hoarded homes that have been impacted by disasters.

A survey of Area Agency on Aging providers resulted in the following comments regarding this question:

- "By the time my organization is contacted a case is typically open with PLI and the house is going to be condemned. So, often clients lose their housing as a result."
- "There are very few resources to help patients with hoarding."
- "… We haven't encountered any resources for hoarding besides a one-time clean up. I have referred to AAA but this has been unsuccessful because the client never 'agrees' to the assistance or support."
- "…However, the HD resident soon ends up in the same situation since there are no agencies that provide professional counseling or mental health assistance. Protective services, Aging services and Aging waiver services do not assist in a HD situation. If family doesn't assist the resident will often be placed in a SNF."
- "We are working thru it as often, people will loose [sic] their housing as a result."

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

The federal government can best help ACDHS assist older adults and others with hoarding disorder through increased funding – expanding eligible services and people. Potential solutions include:

- Centers for Medicare and Medicaid Services (CMS) could require all health insurance providers (including commercial insurance and Medicare Advantage plans) to reimburse for case management, mobile therapy and in-home services. CMS could additionally change the rules to allow for travel time to be reimbursable for community-based and in-home programs. CMS could also work to expand the availability of simple and free telehealth services specifically for hoarding. We believe this would greatly expand the ability of our providers to offer needed services.

- Provide more funding to states for home repair programs for low-income, disabled and senior individuals and homemaker services, chore services, decluttering helpers and cleanouts/cleanups for seniors and people with mental health and/or physical health disabilities.

- Work with the National Voluntary Organizations Active in Disasters (VOAD) to identify VOAD partners who already assist with debris removal for disasters and train them to help with cleanouts in the homes of people who hoard that have been impacted by a natural or manmade disaster.

- Fund more research into the causes of hoarding as well as evidence-based practices for treating hoarding disorder given that it has been classified as its own disorder in the Diagnostic and Statistical Manual of Mental Disorders since 2013.

- Due to the effects of hoarding disorder symptoms on those in close proximity to the individual, there is a need for specialized funding for more shelter or housing for older adults and for older

adults with hoarding disorders. These shelters would allow for individuals to have their own space and to not adversely affect others who are experiencing homelessness and their own difficulties.

Providers submitted the following solutions to a survey distributed by the Area Agency on Aging:

- "Funding for people to help with clutter or a way to connect with volunteers who are willing to do so."
- "Providing a grant to the Department of Aging to help these folks would be very helpful."
- "More funding for people/programs to help residents unclutter/clean/make repairs to their homes or have a transition out of the home plan."
- "Provide practical free/low-cost resources/program to help individuals with HD to efficiently cleanup/reduce the hoard, so that individuals can be safely discharged home in a timely manner."
- "Fund appropriate care without traumatizing the person hoarding."
- "Provide workers who will actually come and work with individuals, wanted or not."
- "Follow up with HUD guidelines."
- "Provide grants and or fund companies to assist older adults with this issue."
- "Provide funding to the Area Agency on Aging to assist seniors when at risk for eviction. Aging Waiver (Community Health Choices) will only provide cleaning services for pest removal. Mandate that the providers will provide deep cleaning services for HD seniors at risk of eviction."
- "Assist MH therapists to receive no or low-cost training/credentialing to provide help. Work with insurance to cover this disorder as well as costs to clean up."

Statement from Athens City-County Health Department

Athens City-County Health Department
happy. healthy. prosperous.

April 12, 2024

Attn: Senate Special Committee on Aging

RE: Impact of hoarding disorder on older adults

Dear Committee Members,

I first want to thank you for your interest in this matter. This is a serious issue that has not received enough attention and consideration in how to address it.

As a brief background, I am employed as an Environmental Health Director at a small county health department in rural Southeast Ohio. In my 24 years of working in this field, I have been involved in multiple hoarding situations each year to varying degrees. My role has been through an enforcing public health and safe housing concerns and violations. From my experience, approaching a hoarding situation from only an enforcement angle will not result in a positive outcome and needs a holistic approach from multiple agencies with different expertise. This has been very difficult in such a small community with limited resources.

More to the point, what I have experienced is the individuals living in a hoarding home are most often older adults who have felt isolated from family, friends, and their community. Often the immediate community has isolated themselves from those individuals living in the hoarding homes due to prejudices, frustration, or other reasons, resulting in the individual becoming more isolated. This often results in complaints filed with our office regarding public health concerns. In responding to these complaints, we are often responding to owner occupied dwellings. Unfortunately, this interaction is often the only interaction our agency has with the individual, which furthers the feeling of isolation. If we cannot gain access to the inside of the home, this does not address the significant hoarding concerns that often include potential risks that can endanger the individuals occupying the home.

My office will always address public health violations that directly affect the public health which more than often are outside the home. However, issuing notices of violations without additional resources results in little improvement to the

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situation since we are not addressing the underlying issue of mental health and often lack of resources both financially and socially since the individual often is very isolated.

Our office often works with social services including adult protective services, department of developmental disabilities, and others to gain access inside the home and try to build upon any relationships the individuals may have. However, these agencies often have limited resources and or jurisdiction to intervene. When there has been this limited intervention, the most successful cases have resulted in limited remediation in the form of removal of solid waste.

From my experience, the only hoarding case that was abated and successfully resolved long term was a result of multiple factors. First, there was someone the individual living in the hoarding situation trusted. The individual was receptive to assistance, the individual had orders to abate the solid waste nuisance, and there were multiple agencies working with them including a local community group. With this in mind, our agency is actively trying to build a coalition of agencies and community groups to further this discussion to see what limited resources are currently available.

I firmly believe to successfully address hoarding situations whether it is in rural Appalachian Ohio or in urban New York, there must be funding available to provide an appropriate number of social service workers, mental health counselling, and abatement resources. We are all looking for a silver bullet to solve problems, but it often takes many small pieces from many places coming together to create real change.

I can go on for much longer, but I know your time is valuable and you are hopefully looking over a lot of responses to hoarding, so in conclusion, any funding and resources that can be allocated to this issue will be greatly appreciated from this community in rural Appalachia.

Statement from Katie Catchmark, Deputy Director, Berks County Area Agency on Aging (Pennsylvania)

Submitted on April 12, 2024

1. **How has hoarding disorder impacted your community, particularly older adults and people with disabilities?**

   Generally, our agency encounters older adults with hoarding disorders when it starts to effect their ability to maintain housing; or maintain or obtain care in the home. Most often the hoarded homes we see are also unsanitary and have accumulated trash. Hoarding becomes a particular problem in our high rises when fumigation is required (most commonly bed bugs.)

   Our Agency has seen situations were hoarding effects the older adult's ability to maintain good health and hygiene when their toilet, bathtub, sink, stove or refrigerator are inaccessible.

2. **How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?**

   It is difficult to find caregivers to provide care in hoarded homes. This is due to safety concerns or concerns of bed bugs.

   Hoarding disorder can also make it difficult to assist older adults with applying for benefits. It is often had to access/ find record in hoarded home and new mail if often misplaced.

3. **How has your organization responded to hoarding disorder, including establishing new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?**
   Our agency has not established any unique initiatives, but would be interested in hearing what successes other agencies have had.

4. **How can the federal government help your organization assist older adults and others with hoarding disorder?**

   In general, it is difficult for older adults to access therapist who accept Medicare.

Katie Catchmark
Deputy Director

Berks County
Area Agency on Aging
Building Partnerships
Strengthening Communities
Enhancing Quality of Life

Berks County Services Center
633 Court Street, 8th Floor
Reading, PA 19601

Statement from the Bucks County Commission

Office of Public Information
55 East Court Street, 5TH Floor
Doylestown, Pa. 18901
215-348-6415

County Commissioners
Robert J. Harvie Jr., *Chair*
Diane M. Ellis-Marseglia, LCSW, *Vice Chair*
Gene DiGirolamo, *Secretary*

Douglas Hartman
Research and Policy Analyst
Chairman Bob Casey
U.S. Senate Special Committee on Aging
G-16 Dirksen Senate Office Building
Washington, DC 20510

Dear Mr Hartman

Please accept the Bucks County Commissioner's letter of information related to the RFI on Hoarding and aging. We sincerely appreciate the opportunity to respond and are doing this along with our Bucks County Human Services Department and our Bucks County Area Agency on Aging,

The RFI requests responses on the following questions:

1. **How has hoarding disorder impacted your community, particularly older adults and people with disabilities?**

   Hoarding affects Bucks County residents who are older and those with disabilities disproportionately lowering the quality of life for the individual, and can in turn reduce the number of years off of their lifetime. We see this when first responders are called to a home, for example, where there

is a home in which has a large hoard and they are unable to rescue the individual due to the heavy content being in the way of a life saving rescue. Not to mention, placing our first responders in undue harms way to try and save a life if in the case of fire, flood, etc. We find that within the community, an individual's hoard not only affects their homes, properties, and health, but affects their neighbor's as well. Many times, the infestations that occur, tend to spread quit easily to next door neighbors and beyond, causing mosquito, termites, molds, hazard waste products, etc. on to the neighborhood where the individual with hoarding disorder resides. We see that hoarding disorder tends to be a trend higher in older adults and persons with disabilities because they simply cannot either afford the upkeep of their home, have the physical ability to maintain their homes, or have such severe decline in mental health that the hoarding becomes a mere symptom of something greater that is affecting the individuals health care needs.

Because of the debilitating effects of hoarding, many victims isolate or are scorned by family and friends. This means they have little support in overcoming their disorder and often no one to support or assist them in any attempt to clean-out the hoard. Hence, the hoarding actions become unsurmountable, and the victim gives up any hope of clearing their homes or seeking mental health intervention. Eventually they succumb to what is called "clutter blindness" where basically they are unable to discern between what would be a health space or unhealthy space.

2. **How has hoarding disorder impacted your organization, particular in its ability to carry out its mission?**

As commissioners representing our county government, we are tasked with maintaining and protecting the health and safety of our residents. Hoarding stands in the way of our ability to do this because laws prevent us from entering or

inspecting homes and treating psychological illness. While we can inspect businesses and apartments for chemical and fire hazards we are limited within an individual's home. In turn, we cannot keep neighborhoods safe from fires or infestations that can spread from these homes that can cause disease or unsafe / sanitary living conditions for all who are affected directly or indirectly. Our limitations are particularly egregious when it comes to the elderly and disabled populations as they are most likely to suffer from the illnesses, injuries, and fires that result from hoarding and are the least able to correct their living conditions. These are some of the most vulnerable populations in which we strive to serve.

3. **How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?**

Bucks County Commissioners established a Hoarding task Force in 2016. While initially well-organized and responsive, changes in agency and government leadership and the COVID-19 pandemic resulted in a lapse and the task Force was re-introduced in 2023.

This Task Force requires the time and energy of many members of the community including: township inspectors, animal control officers, police officers, fire inspectors, social workers, health department inspectors, members of area agency on aging, child welfare, behavioral health, and lawyers. The hours that must be expended on the Hoarding Task Force are exacerbated by the inability to legally enter homes and the need to explore and formulate plans for ways to gain the homeowners' attention and willingness to cooperate.

There are several incidents where hoarding was known but the inability to intervene resulted in fire where victims died. Other victims have been rescued by EMT's, taken to local hospitals for care, and returned to unhealthy hoarding conditions where their poor health was exacerbated and more emergency calls and hospitalizations result, also putting the first responders in continued danger.

4. **How can the federal government help your organization assist older adults and others with hoarding disorder?**

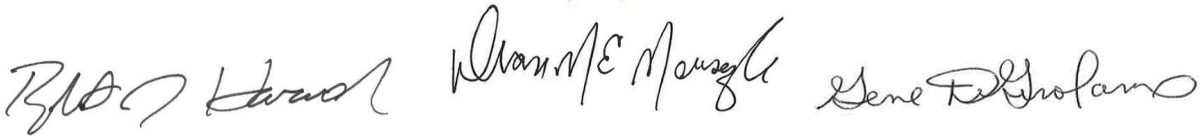
The two biggest ways the federal Government can assist us is in giving local governments or quasi-government agencies the ability to mandate clean-up of hoarding conditions and require mental health treatment of those involved with hoarding. We know that mandatory clean outs can result in the individual who suffers from hoarding disorder to have even more decompensated mental health response including suicidal thinking, when the hoard is being forcefully cleaned out. We would like the funding to be able to provide not only clean out services, but comprehensive and compassionate organizing and case management services to work with affected individuals in a loving and supportive way to foster such change. This takes time, thoughtfulness, and care.

We are prevented from saving lives because of regulations that deny entry into a home, even when there is knowledge of a possible electrical, fire, or air quality hazard. Moreover, while hoarding is a recognized mental health disorder, and victims can improve with treatment, there is no incentive or requirement for treatment. (ICD –10-CM: F42.3)

Making it mandatory for first responders, local government inspectors, social workers, and medical professionals to report

hoarding and requiring health departments (or their equivalent) to investigate would be a major start.

Sincerely,



Robert J. Harvie, Jr. Diane Ellis-Marseglia, LCSW Gene DiGirolamo

Statement from Barbara Paul, RN, Director of Long Term Care, Office of Human Services, Inc. (Area Agency on Aging for Cameron, Elk, and McKean Counties in Pennsylvania)

Submitted on April 3, 2024

Survey Questions:

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

   How timely of a question. This past weekend in Elk County there was a fire and two older adults perished in the fire. "Rumor" in this small community is this was a hoarding situation. Seeing the aftermath of the fire I am inclined to believe that rumor. The very sad reality is no one will ever know 100% for certain if the hoarding impacted the probability of survival for these 2 older adults. In another situation of a fire in Johnsonburg a few years ago another older adult perished in a fire and fire personnel could hear the individual yelling for help yet could not get to her due to the hoarding. This was an older adult still working, not incapacitated in any way.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

   Most often our Area Agency on Aging is impacted by hoarding concerns when family is frustrated and/or providers go into homes and discover "hoarding" and want the situation "cleaned up" and call their concerns into Older Adult Protective Services. The difficulty is the Older Adult doesn't automatically become incapacitated at the age of 60 as folks would like to believe. Many older adults 60 and over are fully functional and cognitively intact-some still working full time jobs. OAPS does not have the ability to force individuals to "clean up". And in some cases when we have had concerns for an individuals safety if not cleaned up (and the older adult met the definition of an Older Adult in need of protection) the Area Agency on Aging spent thousands of dollars to clean spaces up-and that is tax payer money.

   Hoarding is a very difficult and complex problem. Hoarding is a mental health "diagnosis" according to the DSM 5: ***Category: Obsessive-Compulsive and Related*** *Disorders.* ***Introduction.*** *Hoarding disorder* ***is a*** *DSM-5 (Diagnostic* ***and*** *Statistical* ***Manual of Mental*** *Disorders* ***5th ed.)*** *diagnosis assigned to individuals who excessively save items and the idea of discarding items causes extreme stress* **.**

Yet, despite the fact that Hoarding is a mental health diagnosis the Area Agency on Aging is frequently asked to develop "hoarding task force". Hoarding is not unique to older adults so I am not sure why the AAA would be the expert in this and should lead a task force. Another major issue to dealing with Hoarding for this agency is how do we get mental health staff to go into the homes and assist with diagnosis and treatment of the underlying issues? The problem is in the home and not in a therapists office.

In our area another stumbling block we have is code enforcement. We are rural; in some areas we have a code enforcement and in other we do not. Code Enforcement does not always have the authority to intervene in these situations either and have different rules in different areas.

Another issue eluded to earlier is funding; who pays for the clean up? which can be very expensive depending on what type of hoarding whether it be animal, "stuff", or combination.

3. How has your organization responded to hoarding disorder, including establishing new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

We respond to every single situation uniquely to that individual. We work with family, friends, neighbors and most importantly the older adult. If the Older Adult is capable of making informed decisions often times we do nothing but make clear to the older adult the risks of their situation and not making changes and if the older adult accepts those risks we cannot force change. We may make referrals to mental health; however, to my knowledge hoarding alone is not a reason for mental health to get involved. In a perfect world when we have an older adult involved in a hoarding situation; we find ways to get the clean up and would get mental health involved to provide services and supports ongoing to prevent a back slide into the same situation. In several occasions over the past few years we have sent our own staff to "clean up" and paid for trash bins; but this only puts a band aid on the situation; the underlying mental health diagnosis is left untreated.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

Resources is always an issue: funding can be limited and seems like we are begging family and various human services organizations for monetary assistance in clean up costs. Sometimes we get a little money from various sources that helps but then at the end of the day it is the tax payers that are paying for cleanups. Would also be great if Mental Health Organizations would be mandated to come up with a Hoarding Task Force unique to their area. They would not have to meet monthly, maybe even in smaller areas

only when there is a problematic situations. This is not a diagnosis unique to older adults. It would be nice to have a “subject matter expert” group to go to and get assistance more timely without having to beg for help for folks.

Barbara Paul, RN
Office of Human Services, Inc. (Area Agency on Aging for Cameron, Elk and McKean Counties)
Director Long Term Care
Protective Services, Caregiver Support Program, OPTIONs and Dom Care
108 Center Street
Ridgway, PA 15853

Statement from Diane M. Terada, Division Administrator, Catholic Charities Hawai'i

Submitted on April 6, 2024

Thank you for looking into the impact of hoarding on older adults. We are seeing this more frequently and more must be done to address the issue. Especially since we are also seeing more older adults living alone w/ little or no support system.

- **How has hoarding disorder impacted your community, particularly older adults and people with disabilities?**
    - Eviction and homelessness – we see older adults who are unable to pass housing inspections and as a result, are evicted from their senior affordable housing units.
    - Impact on support system – relatives may become frustrated and distance themselves from the older adult who is hoarding, the older adult may resist aging network provider efforts to engage family support due to shame, etc.
    - Safety and health – even for those older adults who are homeowners, their living environment can become unsafe and unhealthy.
        - Example: an elderly (80's) widow owns her own home but lives in her car because her house is uninhabitable due to hoarding and subsequent disrepair (pipe broke; house got flooded; we suspect mold is developing). Only child lives on the East Coast. Refuses to have repairs done; refuses to throw away even old newspaper articles.

- **How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?**
    - Our goal is to help older adults remain independent in their own homes. We cannot do this if they are unable to meet housing requirements or are not able to maintain safe and healthy living environments. We do not have the financial resources to pay for cleaning or ongoing case management to support older adults with hoarding disorder.

- **How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?**
    - We have used some client financial assistance funds to remove clutter and clean – but only when client is willing AND only if a longer term plan of action can be implemented to ensure that the hoarding does not recur.
        - Example: Elderly female in senior affordable housing was referred by housing management due to impending eviction. She had refused annual housing inspection due to hoarding and neighbors were complaining of odor and bugs emanating from her unit. We were able to send a case manager who was specifically funded by our agency to work with persons w/ dementia who live alone. It took several home visits in order to gain client's trust to allow worker to enter the unit. It then took multiple home

visits to get client to agree to cleaning. Worker arranged for a subsidized cleaning service to continue the ongoing cleaning and also made a referral for a volunteer to visit on a regular basis to encourage client to continue to remove clutter. Client was able to pass housing inspection and continues to remain housed. (FYI, both the case manager and the volunteer are the result of a prior ADPI grant!)

- **How can the federal government help your organization assist older adults and others with hoarding disorder?**
    - Recognize the need for ongoing support – hoarding behavior does not go away.
        - Cleaning clutter is only a partial solution - A one-time clean out is a very short term solution and usually a waste of money. We have seen older adults who will go through trash to pick up items that were just removed from their units, only to put them back.
          However, if an older adult is willing to clean, they need help to do so. Sometimes it is just too overwhelming a task and they don't know where to start OR do not have the physical ability to clean.

        - Addressing Trauma and preventing further trauma – often hoarding is a way that people who have had traumatic events in their lives will try to compensate. You do not want to force a person to have their homes cleaned out as you just add more trauma to their lives.
        - Funding needed for ongoing case management for persons with hoarding disorder and training for therapists specifically to counsel persons with severe hoarding disorder.

Thank you for looking at this issue!

Diane M. Terada
CATHOLIC CHARITIES HAWAI'I
Clarence T. C. Ching Campus
Community & Senior Services Division
Division Administrator

Statement from Lindsay Heckler, Director of Policy, Center for Elder Law & Justice

CENTER FOR ELDER LAW & JUSTICE

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April 12, 2024

United States Senate Special Committee on Aging
Washington, DC 20510-6400

Via email: HoardingDisorder@aging.senate.gov

Re: Hoarding Disorder and Older Request for Information

The Center for Elder Law & Justice (CELJ) thanks the Senate Special Committee on Aging for bringing attention to hoarding disorder (HD) and its impact on older adults and for providing opportunity to submit comments. CELJ is a civil legal services organization fighting for justice, primarily for low-income older adults, in 10 counties in Western New York. For over 40 years, our attorneys stop illegal evictions, save clients homes from foreclosure, put a stop to elder domestic violence, fight for public benefits, work with our local immigrant & refugee populations, and represent grandparents and other kinship care relatives in custody and neglect petitions in family court. We also advocate for systems-wide policy changes, commenting frequently on changes to regulations and working with local elected leaders on legislation that will impact the poor and vulnerable older adults in our area. We believe that independence and dignity are the hallmarks of justice.

We see firsthand how HD impacts our clients ability to age in place and with dignity and offer the following feedback:

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Older adults and people with disabilities are denied life (and dignity) saving home care and other services because of the condition of their living environment. Clients who live with HD show a lack of insight into how severe the environmental conditions are, which directly impacts their health and safety. Some examples from our experiences involving clients:

- Hoarded items breed insects and rodents which have resulted in code violations and health hazards not only for the client but for neighbors and family members.
- Delays in getting emergency services because first responders have to navigate mazes of hoarded items and garbage on the floor.
- Service providers such as home care aides, who cannot provide services due to unsafe conditions.
- Lack of safe discharge from a hospital or nursing home due to the condition of the community home.

Persons living with HD can be reluctant or refuse to accept services or present unwillingness to participate in a 'cleanup' of the home in order to receive various services. This is a barrier to receiving any kind of services and supports, legal, homecare, and other.

The lack of education and specific intervention tips to community based organizations and service providers to work with persons with HD impede our ability to help. In addition, there is an overall lack of financial assistance to offset the costs of cleanouts for persons who are accepting of assistance. Many of our clients are on an extremely limited, fixed income, and are not able to afford the cost of professional cleaning and lack the ability to carry out the cleaning themselves.

The impact of HD on older adults and persons with disabilities cannot be understated. Persons living with HD with no interventional supports often results in hospitalization then institutionalization in a nursing home where the condition goes untreated. We have also worked with clients who faced eviction from their assisted living facility and nursing homes due to HD.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

CELJ's mission is to help older adults age with independence and dignity. Unfortunately serving clients living with HD does directly impacts our ability to not only provide legal advice and representation but connect the client with other services they need. For example, many of our clients are homebound, lack transportation, and have varying challenges with private/phone access. As such we visit these clients in their homes. Depending on the extent of the hoarding situation, it can be difficult to impossible to meet with clients in their homes. Staff can be at risk of injury when floors are covered with items and clients refuse to allow staff inside to assist. We have also had clients whose homes were 'leaning' from the weight of the items. HD presents a lot of challenges in our office to not only try to establish an attorney-client relationship but continuing to provide legal representation, counsel, and advice.

CELJ also serves as court appointed guardian for persons in Erie County, where the court has determined they lack legal capacity and who require assistance to meet their needs. Trying to clean out real property and apartments where hoarding is present is costly and many of our clients (both in the Guardianship Unit and other units) do not have the resources to get this done.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

CELJ helped revive the Council on Elder Abuse Hoarding Committee[1] that meets once per month to discuss cases, resources and other topics in housing. A social worker with CELJ chairs the committee and has created guides/information on various subtopics of hoarding that includes: digital hoarding, vehicles, animal hoarding, hoarding behaviors with dementia, bed bugs and infestations, hoarding by age, clutter levels and intervention or decluttering tips. CELJ also has a team of social workers who will work with clients who have HD.

[1] https://www.councilonelderabuse.org/services.php?PageTitle=Hoarding%20Committee&SPID=19&PCID=3

Through working with, and outside of, the hoarding committee, CELJ has helped participate in 'train the trainer' sessions, providing teachings about HD and offering links to help staff in other organizations learn about community services and groups. A major challenge, outside of funding, is these trainings and the work of the hoarding committee is dependent on staff remaining in their organization. A robust group and organizational support can lose footing when staff who are trained retire or are directed to other priorities.

CELJ also operates a financial management program, in contract with Lifespan of Rochester that provides clients with a volunteer to assist with budgeting, organizing and opening mail, linkage to services, and preventing financial exploitation.[2] Clients with hoarding behaviors are referred to this program and the simple acts of a volunteer being able to assist with organizing and shredding/filing just financial papers and mail, has made a positive impact in these clients lives.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

There needs to be more federally funded/supported research on hoarding disorders: how it starts and effective interventions across all ages and disabilities. There must also be federally available funding dedicated to hoarding programs such as cleaning services, specialized mental health treatment, support groups, etc. Monies could be set aside through the Older Americans Act funding or various housing programs that can be specifically required to cover the costs of clean outs for homes and apartments. Lastly, as the federal government continues its initiatives/actions to achieve mental health parity in Medicare (and other insurances/programs like Medicaid), it is important that coverage is available for mental health counselors, caseworkers, social workers and others to work with persons who have HD and need intensive treatment and follow-up.

Thank you again for this opportunity to provide feedback on HD and its impact on older adults, persons with disabilities, and community-based organizations who serve them. I am available to connect you with our social workers, attorneys and other staff to provide you with further information and connections, including older adults with HD, and the Council on Elder Abuse Hoarding Committee.

Regards,

Lindsay Heckler
Director of Policy
[redacted]

[2] https://www.lifespan-roch.org/financial

Statement from Chicagoland Hoarding Task Force

United State Senate
Special Committee on Aging
Washington, DC
Attn: Doug Hartman-Staff

April 15, 2024

The Chicagoland Hoarding Task Force was formed in 2017 to train professionals, assist in the implementation of evidence-based procedures and interventions, and coordinate sharing resources for those struggling with hoarding and its challenges. We are a group of volunteers working in conjunction with the non-profit Midwest OCD. Our Task Force is a small group of dedicated volunteers from diverse backgrounds such as Mental Health, City of Chicago, Professional Organizing and Academics to name a few.

We have responded individually to over 30 inquiries in 2022 and 27 inquiries in 2023 for help with Hoarding Disorder from individuals, families, medical professionals, and therapists seeking help. The majority of those seeking help were for the greater Chicagoland Area residents over 60 years old.

The Task Force offered the community "OCD and Hoarding Expo" in 2019, 2021 and 2023 with leading experts from the United States. We offered the events at no charge to all participants and ask local businesses to sponsor the events. In 2023 we had over 245 people sign up to watch live or the recording of the event with participants from all over the country and several from international locations. Clearly, there is a need for free education and for additional resources throughout the country. The Task Force operates from a shoestring budget of donations which has been more difficult to obtain since the pandemic.

In 2023, the Task Force trained members of the City of Chicago-Department of Family and Support Services-Senior Services Division to conduct educational workshops and Buried in Treasures 8 weeks Intensive Groups to residents of Chicago age 60 and over. In 2019, the Task Force trained over 45 City of Chicago building inspectors and police officers.

In 2025, we have many plans to expand the training to other communities in the greater Chicago area. The biggest obstacle the Task Force faces is funding to pay for our professional trainers and administrative assistance to coordinate our free "OCD & Hoarding Expo". We want to offer evidence based no fee support and education to First Responders, Adult Protective Services, Housing Agencies, Landlords and of course, to family and friends of seniors with Hoarding Disorder.

One of the aspirational goals is to allow our senior residents to age in place in a safe manner while maintaining healthy relationships with family, friends, neighbors, and their community. If we were to receive funds from the federal government, we would be able to greatly increase the training, resources, and direct support to our community, many of whom are struggling or at risk for hoarding challenges. Thank you for your attention to this serious problem facing many of our current and future seniors.

Warmly,

Kathleen Crombie, MA, MEd. (co-chair)
[redacted]
Leslie Hatch Gail, PhD (co-chair)
Gregory Chasson, PhD
Yuzu Sasaki Byrne, CPO, CPC, ACC (secretary)
Alexandra Smith Wieringa, LCSW (treasurer)
Julianne Pojas, PsyD
Lisa Joy Rosing

Statement from Columbia/Montour Aging Office, Inc. (Pennsylvania)

Submitted on April 9, 2024

Hoarding Survey

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

   Hoarding causes safety risks for the consumers we deal with such as: fall risk, fire hazards, pests and bug infestations that spread to neighbors. The consumer themselves is generally socially isolated and often ostracized by local community if the condition of the home is bad enough for others to know what is going on. Oftentimes, access to kitchen is diminished causing poor nutrition. The homes can be condemned causing homelessness and decreased property values for neighboring homes.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

   Hoarding has had a significant negative financial impact on our organization. These cases are dealt with by Protective Service staff, taking time and resources away from other at risk individuals. We are often paying for emergency shelter due to homelessness, extreme clean ups and pest control to get the residence livable. These costs can total several thousand dollars for one consumer. There often are no options and resources available to maintain it after initial clean up. We are a rural area with minimal resources to help people manage the hoarding condition and often times, homes are back to their original hoarding condition within months. Oftentimes these consumers hoard animals as well, taking more time and energy and taxing other community programs to get shelter and proper care for the animals.

3. How has your organization responded to hoarding disorder, including establishing new or unique initiatives? What, If any, challenges has your organization faced while implementing that response?

   Our agency budgets a considerable amount of our allocated protective service dollars to emergency shelter, extreme clean up and pest control. We are a small rural community and often have to utilize other community service agencies to assist with the cost. We face challenges in the lack of support that is available in our area to assist hoarding consumers and give them good coping skills and resources to keep them from doing this

over and over. We struggle with finding appropriate placement and care for hoarded animals.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

   More money needs allocated to services for cleanup and also mental health counseling to provide consumers with support and services to help maintain after clean up. Cleaning up the environment alone is not going to make someone stop this behavior. They need ongoing intensive mental health support that our local mental health programs are not equipped to handle at this time.

Statement from Sean M. Benoit, Director of Litigation, Community Health Law Project

COMMUNITY HEALTH LAW PROJECT

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New Jersey's Legal and Advocacy Organization For People With Disabilities

April 15, 2024

Via Electronic Mail
United States Senate
Special Committee on Aging
Washington, DC 20510-6400

Re: Reply to Request for Information on Hoarding Disorders

Dear Honorable Committee Members:

The Community Health Law Project is writing to provide a written response to the inquires contained in the March 19, 2024 request for information regarding hoarding disorders. As laid out in more detail below, hoarding disorders have a negative impact on the elderly and people with disabilities in that it can cause housing instability and lead to evictions and homelessness. In order to combat this problem, funding is needed to provide legal services to prevent evictions, as well as funding to provide cleaning services and therapeutic services to address the hoarding disability so that housing for those afflicted by hoarding disorder can be saved.

Background

The Community Health Law Project ("CHLP") is a New Jersey based non-profit law firm that provides free legal representation and advocacy to low-income people with disabilities. Since 1976, we have provided representation and advocacy in such areas as public entitlements, social security, domestic violence, and tenant's rights. We have attorneys and advocates on staff to assist people in need throughout the entire state.

In the area of tenant's rights, we have provided legal representation to elderly tenants and tenants with disabilities who are facing eviction from their homes due to their hoarding disorder. The hoarding disorder has often created an environment within the home that is in violation of their leases due to unsanitary conditions and safety or fire hazards. Our staff has worked diligently, for decades, to try to prevent the homelessness of people with hoarding disorder.

Question 1: How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

The biggest impact hoarding has had within the clientele that we service is that it has caused housing instability. Specifically, our elderly clients and clients with disabilities have faced eviction from their homes due to their hoarding disorder.

Often our clients have been hoarding for a long time, years, if not decades, and it has created an unsanitary condition in their homes, or a safety or fire hazard within the home, and they are now in violation of their leases. Sometimes the landlords are doing their own housing inspections and issuing notices and citations to the tenant. Or other times, state or local agencies, like the local board of health, is conducting an inspection and citing the property. Unfortunately, these situations often lead to the landlord starting the eviction process against the tenant.

If the eviction is successful, the person with the hoarding disorder will become homeless. However, the ramifications of such an action do not just stop there. In New Jersey, once an eviction is granted, it is a public record that will remain visible to anyone accessing the court database for a duration of at least seven years. Under New Jersey's current court rules, an eviction is only excluded from public access if the matter results in a dismissal or it has been greater than seven years since the eviction was entered. N.J. Court R. 1:38-3(f)(11). Any prospective landlord or housing provider will be able to see the person's eviction and the reasons for it, specifically the hoarding disorder. Securing future housing becomes difficult if not impossible.

Additionally, a majority of our elderly clients and clients with disabilities are low-income, so their housing is usually subsidized in some form. Housing subsidies range from Housing Choice Vouchers (Section 8) to public housing through local public housing authorities. All of these types of subsidized housing have various regulations and administrative plans that govern how they operate, including eligibility requirements. The majority of these regulatory schemes and administrative plans have a provision that state when the applicant has been previously evicted for cause from subsidized housing, they can be denied eligibility. As a result, our clients who have been evicted for their hoarding disorder cannot secure affordable subsidized housing again, and their homelessness will persist.

Question 2: How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

CHLP's mission is to provide legal and advocacy services to persons with disabilities and chronic health conditions. As laid out above, hoarding disorder primarily impacts our clientele in terms of their housing. We strive to ensure our clients have stable affordable housing. Being denied access to stable housing has a down spiral effect on our clients physical and mental health. Given that hoarding disorder will often lead to eviction, it presents a huge challenge to us in achieving our goal of stable housing for our clients.

Question 3: How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

In order to assist our clients and maintain their housing when they have a hoarding disorder, CHLP will advocate zealously and attempt to prevent the matter from even getting to court. In this type of a situation, when a client comes to us and their housing is at risk due to a hoarding disorder, we will request a reasonable accommodation from the housing provider.

Under the Fair Housing Act, a housing provider is required to provide a reasonable accommodation to a tenant with a disability when it is necessary to ensure the tenant has the same opportunity to use and enjoy the dwelling. 42 U.S.C. §3604(f)(3)(B). In the case of someone with a hoarding disorder, a good example of a reasonable accommodation is to request time to clean the home out and time to obtain therapeutic services to address the hoarding disorder. This type of accommodation is not always an immediate fix since it does take time and effort with participating in therapy to ensure that the hoarding disorder does not arise again to the point where the housing is unsanitary or becomes a fire or safety hazard again.

Unfortunately, this advocacy is not always successful. There are virtually no agencies or organizations that offer pro bono decluttering services for people with a hoarding disability in New Jersey. There is no funding for these types of services. Additionally, for elderly people on a fixed, or low, income, they cannot afford a private cleaning service to come and clean their residence out.

Also, with non-profit organizations like ours, we do not have the funds to be able to pay to clean out their residences, nor do we have therapeutic staff that can provide the therapy and social work services that the client needs to successfully clean out their home and maintain it in a habitable condition.

Lastly, if the matter has already proceeded to the point where it is in court and the residence has not been cleaned out, they become difficult matters to be successful in. The landlords will typically have documentation of the condition of the unit, as well as documentation of attempts to get it cleaned out in the past. The landlords can usually meet their burden of proof very easily and the courts will grant the eviction.

Question 4: How can the federal government help your organization assist older adults and others with hoarding disorder?

When it comes to housing stability for elderly people and people with disabilities who have hoarding disorder, more funding is needed to provide services to stabilize their housing.

More funding is needed to ensure that more individuals with hoarding disorder have access to the necessary legal services to assist them. Having a well-trained attorney there to advocate for their rights under the law is necessary to ensure housing stability and to have the landlord comply with

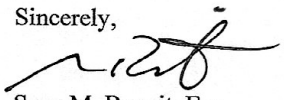
the Fair Housing Act. Funding is also needed for non-profit organizations like ours to hire social workers and therapists to provide the necessary therapeutic support to this population.

Lastly, funding is also needed to provide decluttering services. The services need to be able to clean out the residence so that it is habitable and provide continuing decluttering services on a regular basis. Cleaning along with consistent therapy will work best to keep the hoarding disorder from coming back and creating another unsanitary or unsafe condition within the home.

Conclusion

Hoarding disorder in the elderly and people with disabilities has had a significant impact on housing stability. However, with additional funding for proper supports like legal services, decluttering/cleaning services, and therapeutic services, the problem can be addressed effectively.

Sincerely,



Sean M. Benoit, Esq.
Director of Litigation
Community Health Law Project

Statement from Jia Min Cheng, Supervising Attorney, Disability Rights California

Disability Rights California
California's protection & advocacy system

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April 15, 2024

VIA Electronic Mail

United States Senate, Special Committee on Aging
Washington, DC 20510-6400
HoardingDisorder@aging.senate.gov

Re: Senate Special Committee on Aging's request regarding Hoarding Disorder

To the esteemed Senate Special Committee on Aging:

As the largest provider of legal services for people with disabilities in the country, Disability Rights California (DRC) thanks the Senate Special Committee on Aging for providing the opportunity to submit information related to the impact of hoarding disorder on older adults and people with disabilities. DRC is the federally and state-designated protection and advocacy agency for California.[1] We operate a statewide housing helpline, providing free legal services and connection to local social service

[1] Pursuant to the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15001, Pub. L. No. 106-402; the Protection and Advocacy for Mentally Ill Individuals Act, 42 U.S.C. § 10801, Pub. L. No. 102-173; the Rehabilitation Act, 29 U.S.C. § 794e, Pub. L. No. 106-402; the Assistive Technology Act, 29 U.S.C. § 3011-3012, Pub. L. No. 105-394; the Ticket to Work and Work Incentives Improvement Act, 42 U.S.C. § 1320b-20, Pub. L. No. 113-128; the Children's Health Act of 2000, 42 U.S.C. § 300d-53, Pub. L. No. 115-377; and the Help America Vote Act of 2002, 42 U.S.C. § 15461-62, Pub. L. No. 107-252; as well as under Cal. Welf. & Inst. Code § 4900 et seq.

resources. We also provide training and technical assistance to legal aid providers and mental health providers to enhance their services to persons with disabilities. It is based on our extensive advocacy and experience that we offer the following responses.

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Evictions due to hoarding behavior present unique challenges. By law, eviction cases move quickly: tenants generally have three days to "cure or quit" under an eviction notice before a court case for eviction is filed. Certain types of subsidized or affordable housing may provide slightly more time than three days, but not much more. On the other hand, the process of cleaning up a unit with clutter which rises to the level of justifying an eviction is slow and arduous. The difficulty which the tenant faced in discarding possessions is the very behavior they are called upon to address quickly when they are faced with eviction. In addition to mental health barriers to cleaning up quickly, persons with physical disabilities and older adults often grapple with physical barriers to the clean up.

As a legal services provider, frequently the point in time in which clients at risk of losing their housing due to behavior related to hoarding disorder (HD) or other disabilities call DRC is when they are at imminent risk of losing their housing. They call when they have received an eviction notice warning that they need to either clean up within a matter of days or move out. At the other end of the eviction spectrum, they call when they have either lost the court case or violated the settlement agreement which would have allowed them to stay provided they clean up their home. In all instances, their options are extremely limited – the decluttering must happen shortly either to keep them housed or as part of the move out process.

During the height of the pandemic when statewide and local eviction moratoria prevented loss of housing due to inability to pay rent because of COVID-19, our legal aid colleagues in the San Francisco Bay Area practicing housing law worked almost exclusively on evictions related to nuisance, a category of eviction under which hoarding falls. Nuisance cases were not covered by COVID-19 tenant protections, and landlords were able to move forward with evictions.

DRC assisted one client, Beth (name changed for confidentiality) from July when she first received a notice of lease violation due to hoarding behavior to the following April when she was able to have a final inspection with her housing provider to clear the violation. Beth's case was a rare best-case scenario—as a repeat DRC client, she contacted DRC early for help immediately after she received a notice of violation; and the housing provider's attorney was well-versed in fair housing law such that he did not aggressively move to evict. With DRC's assistance, Beth requested a reasonable accommodation for more time to cure the violation and the housing provider granted several extensions so Beth could seek support in de-cluttering her apartment. Beth lives in a major metropolitan area with more options for support services and DRC helped Beth explore a number of different options for service providers before finally finding one that would assist Beth with the deep cleaning. A significant contributing factor to Beth's success in preserving her housing was that her housing provider did not proceed straight to the eviction process, giving Beth an extended yet reasonable amount of time to get supports in place. As legal services providers, the situation we see more frequently is a client with little time left because they are already in the midst of the formal eviction process.

As you may know, eviction can be an extraordinarily stressful situation. Throughout my years of practice, I have encountered first-hand and second-hand clients who, in their desperation to be done with the eviction case and keep their housing, sign settlement agreements with terms with which they cannot realistically comply. For evictions because of hoarding behavior, the settlement terms frequently include the tenant agreeing to clean up within a certain timeframe – anywhere from a few weeks to a few months. Such settlement agreements merely postpone the eventual loss of housing if the tenant is lacking mental health supports and support services who can help with the cleaning efforts, and the tenant is unable to find such services in time to comply with the settlement terms in a timely manner. Beth's case took three quarters of a year, with about half of that time trying to connect with different service providers until she found one that could help with the de-cluttering.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Eviction not only has an immediate impact of displacing a household—it presents a host of re-housing challenges, especially due to the fact that an eviction on a housing seeker's record presents an almost insurmountable barrier to getting approved for most housing. The majority of DRC's clients are on fixed incomes (Social Security Retirement, SSDI, SSI, etc.). Subsidized or affordable housing is almost never a replacement option for DRC's clients facing eviction because the waitlists for such housing are long. Compounding the problem, the waitlists in most, if not all, jurisdictions in California are usually closed. The cost of market-rate rental units tends to exceed the fixed incomes of DRC's older clients – a problem increasing with skyrocketing rents in California and across the U.S.

DRC's work with persons at risk of housing loss due to hoarding behavior ranges from providing informational materials to legal representation to enforce laws prohibiting disability discrimination. Most often, we assist clients (such as Beth, as mentioned above) with requesting reasonable accommodations which they need in order to have equal opportunity to use and enjoy their homes, and to stay housed.

For Beth and clients facing the same risk of housing loss, requesting and receiving initial approval of the reasonable accommodation request is merely the first step in resolving the issue jeopardizing their housing stability. Without the attendant services of mental health supports and deep-cleaning assistance, the legal service of obtaining the reasonable accommodation is ultimately rendered meaningless in preserving the client's housing. This is true of the eviction defense legal services as well because even in cases where the tenant successfully defends against the eviction, in severe hoarding cases the landlord is likely to try to evict again soon if the hoarding conditions persist. The "more time" accommodation to clean must be finite in order to be reasonable. The legal services in hoarding cases must always be coupled with social services and healthcare services, particularly mental health, in order to ensure success in the long term and prevent housing loss.

In 2022, DRC added social workers to our staff in order to enhance the quality of our legal work in homelessness prevention. Social work complements our legal work, as clearly demonstrated by our work on hoarding cases. Our social work staff are better-equipped and better-trained than our legal staff to help connect clients to local support services once our legal staff have set the stage by helping the client procure the reasonable accommodation(s). In addition to connection to formal service providers, our social workers can counsel and coach clients on how they may be able to ask for help from friends, family, and

neighbors—an invaluable service in hoarding cases since the clients have a finite amount of time to clean and may be isolated from their social connections.

While DRC takes an interdisciplinary approach to assisting our clients, our approach is still limited due to the complex nature of hoarding cases and external factors continue to impact clients' long-term housing stability in such cases. These external factors include the paucity of free or low-cost service providers to do the on-the-ground work of cleaning and healthcare providers to support clients in order to avoid a repeat of severe clutter. We can help the clients get the reasonable accommodation(s), and we can recommend and refer clients to outside services, but we often do find out whether the services were actually available or ultimately fruitful.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

In August 2022, DRC organized a statewide training on "Hoarding and Harm Reduction" to legal services and mental health services providers. We hired experts Dr. Danielle Schlichter and Dr. Jose-Antonio Aguilar to provide the training in conjunction with DRC staff, and we provided Minimum Continuing Legal Education credit with an Elimination of Bias credit. 248 providers throughout California attended the live virtual training.

DRC also routinely provides technical assistance to other organizations and agencies for cases involving HD, or other disabilities manifesting in hoarding behavior. As recently as ten days ago, we received a request from the Alameda City Attorney's office for technical assistance on a case involving an older adult whose relationship with his landlord has grown

contentious likely because of hoarding. We provided some initial information and remain available for ongoing technical assistance.

DRC is exploring hosting Hoarding Workgroups where medical experts on hoarding would hold unstructured trainings where professionals can bring their hoarding cases and the experts would help them strategize how to deal with their clients with HD. We continue to develop our expertise on these types of cases but, with our budget constraints and limited staff capacity to fulfill DRC's expansive mission, at this time we have generally folded this work into our broader homelessness prevention and anti-discrimination work.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

We hope that Beth's case demonstrates that time is a key factor in success in preventing housing loss for older adults and persons with disabilities due to hoarding. Eviction, or the threat of it, should be the absolute last resort in addressing hoarding behavior because the timelines do not match up with the mental health and practical needs of older adults and persons with disabilities.

We recommend that the federal government invest in prevention resources such as increased and low-barrier access to social services and mental health care, with a focus on early detection and treatment of the myriad conditions which can eventually lead to severe hoarding. This is especially needed in areas with fewer resources for persons who live far away from the higher-resourced major metropolitan areas. Education campaigns about mental health in order to reduce stigma will also serve a prevention purpose. Finally, to the extent in which the federal government can explicitly incentivize coordination of services and

reduce silos among the web of legal, social, and healthcare providers, we believe such coordination to be vital in ensuring that persons with disabilities remain stably housed while enjoying equal rights, dignity, choice, independence and freedom from discrimination.

Thank you again to each member of the Senate Special Committee on Aging for investigating this important issue impacting your constituents and communities. If you have any further questions, please contact me at [redacted]

Respectfully submitted,

Jia Min Cheng, J.D., Esq.
Supervising Attorney

Statement from Elder Services of Berkshire County, Inc

Elder Services of Berkshire County, Inc.
50 YEARS ANNIVERSARY

877 South Street Suite 4 East, Pittsfield, MA01201
Telephone (413) 499-0524
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April 12, 2024

Douglas Hartman
Research and Policy Analyst
Chairman Bob Casey
U.S. Senate Special Committee on Aging
G-16 Dirksen Senate Office Building
Washington, DC 20510

Dear Mr. Hartman,

As the federally designated Area Agency on Aging and the state-designated Aging Services Access Point, Elder Services of Berkshire County, Inc. (ESBCI) is mission-driven to provide Berkshire County seniors, caregivers, and individuals with disabilities the opportunity to live with dignity, independence, and self-determination while achieving the highest level of quality of life. ESBCI offers a range of programs and services to help older adults continue to live independently in their own homes and communities across the county's 946 square miles.

We appreciate this opportunity to submit these written comments regarding the impact Hoarding Disorder has on the older adults we serve, their family members and our community as a whole.

1. *How has hoarding disorder impacted your community, particularly older adults and people with disabilities?*

At ESBCI, we have witnessed the impacts of Hoarding Disorder on older adults and people with disabilities in a multitude of ways. Due to the rural nature of our area, some individuals live in homes with excessive clutter and squalor for decades before their situation comes to the attention of others. Often a serious medical event or fire results with EMS being called to the home and as a result, the local health department is notified of the condition of the home. At this point, the consequences for those with Hoarding Disorder include eviction from their home or their home being condemned, potentially facing homelessness, estrangement from friends and family, increased isolation, and the impact this has on their mental health and/or physical health. Without clear pathways in their home, an individual is at risk of falling and/or is prevented from using an essential assistive device such as a walker or wheelchair. Exiting in the home quickly in the event of an emergency, such as a fire, becomes more difficult, if not impossible, when extensive clutter blocks the egresses. There is also a significant financial toll Hoarding Disorder can create, as many people on a fixed income cannot afford the cost to de-clutter their home. Additionally, many older adults with Hoarding Disorder are not physically able to de-clutter, again creating the need to hire this assistance. It can also affect the safety and well-being of their neighbors. This is especially true for those individuals who live in subsidized housing site where the potential of a fire due to extensive clutter could be devastating.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

While ESBCI makes every effort to assist those with Hoarding Disorder, it can be difficult to provide the necessary services to those individuals whose homes violate local safety and sanitation codes. For those who are accepting of our services, the personal care aides and homemakers, at times, put their own safety at risk by working in these homes and as a result, are reluctant to service these individuals long term. Interventions our agency can offer to those with Hoarding Disorder include behavioral health services through our Elder Mental Health Outreach team, offering limited financial assistance for heavy cleanouts, collaborating with Adult Protective Services and local health departments along with making referrals to Community Legal Aid and Tenancy Preservation agencies. Some situations are beyond the scope of what ESBCI can provide, such as meeting the high need for intense behavioral health services, extensive financial assistance needed to complete de-cluttering services, and filling the gap of trained, in-home de-cluttering partners or peer support specialists. There is a significant lack of trained de-cluttering professionals and behavioral health providers to support those with Hoarding Disorder in a trauma-informed way.

3.How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

Recognizing the need to educate both the public and local professional community on Hoarding Disorder and what is helpful to those with this diagnosis, ESBCI sponsored a free, half-day Hoarding Disorder training in June of 2023 that was open to the public. Presented by two nationally known experts in the field, the event attracted over 60 participants that included licensed clinicians, Adult Protective Services workers, representatives from local housing authorities, code and sanitation enforcement agencies, and other community-based organizations as well as those with lived experience and their family members. Participant surveys from the event were overwhelmingly positive.

4.How can the federal government help your organization assist older adults and others with hoarding disorder?

One of the biggest barriers to addressing Hoarding Disorder is the lack of resources. Funds to provide educational opportunities and/or provide more resources to assist those with Hoarding Disorder, such as trained peer support specialists, clinicians, and de-cluttering partners. Additionally, assistance to those who are at risk of losing housing due to over-cluttering in their home, such as financial assistance to cover the costs of de-cluttering and alternative housing while a home is being de-cluttered. In addition, a national educational campaign on Hoarding Disorder would help to lessen the stigma associated with it and would encourage the individuals living with excessive clutter to seek help before their situation becomes a crisis.

Respectfully,

Maureen Tuggey
Client Services Director

Hilary Houldsworth, LICSW
Behavioral Health Clinician

Statement from Ashley McCullough, Franklin County, Pennsylvania, Aging Care Manager Supervisor II

Submitted on April 10, 2024

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

   Hoarding impacts older adults' ability to get personal care services in their homes. Sometimes providers are not willing to go into those situations and sometimes older adults are embarrassed to allow help in the home.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

   Sometimes older adults with hoarding issues are not able to get the assistance they need which leads to protective services cases. This will sometimes lead to repeat investigations.

3. How has your organization responded to hoarding disorder, including establishing new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

   We have been able to get a contract to clean out homes that are hoarded, through using special funds. If those funds don't continue then we may not be able to offer those services. A challenge would be making sure there is a plan in place to keep the home cleaned up and get services in there so we aren't back to where we started.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

   There need to be more resources through Mental Health to help treat the hoarding disorder as well as help the older adult stay on track. This is a mental health disorder, not an aging disorder.

--

Ashley B. McCullough
Aging Care Manager Supervisor II
600 Norland Ave, Suite 11
Chambersburg, PA 17201

Statement from Rebecca Poole, HQS Support Technician, Housing Opportunities of SWWA (Washington state)

Submitted on April 3, 2024

Hello,

My name is Rebecca Poole and I work at Housing Opportunities of Southwest Washington. I schedule inspections, as well as go on inspections. Since working here, I have seen several cases of hoarding. Due to the Pandemic, we stopped our Annual inspections for 2 years. Since I started in March of 2022 we noticed an increase in the number of tenants with HD. I am always interested to know more information, to find out ways to help these tenants. Here are my answers to the questions that were asked.

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

HD has impacted our communities because it effects more than just the tenant with HD, it effects their neighbors, as well as the landlords. Sometimes negatively a little like just a smell, sometimes worse by bringing bugs and other critters, and a big safety hazard due to fire hazard, not working smoke detectors, and if their unit is above another tenant. It effects the tenants themselves with HD by decreasing their quality of life, as well as the pets and children's lives who reside with them.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

HUD provides standards for our Annual inspections. The main standards are "Safe, Decent and Sanitary." HD usually violates all of these. This causes tenants to be at risk of losing their housing assistance, as well as their housing. A few tenants with HD do recognize it and do seek help, but it's very few. Most do not even realize that is what they have, and we are not able to even suggest that to them. All I am able to do is provide them with resources I know could maybe help them, but if the decide not to follow through with any of the resources, some tenants have lost their housing assistance. Our goal is to get people housed and keep them housed, however HD has made this very difficult with some tenants.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

We have made changes in both directions since I began here. I am less tolerant for tenants who have HD but will not admit or do not recognize it as a disorder and do not make any attempts for change or seeking help. I will give them extra time [with Reasonable Accommodation requests that they must ask for] as well as giving them

phone numbers and websites for resources that could assist them. New changes we're making is for my department, we are carrying over the RA requests made previously in the year, so they do not have to fill out the paperwork again. We are suggesting more frequent inspections than every year. If the tenant is seeking help, and making regular improvements, we are not sending them to Termination.

I have been seeking more help though, especially with those who do not admit anything is wrong. I have even called Adult Protective Services on some but that made no difference as that interview does not have to take place at the tenants residence. Those are the tenants I'm having the most issues with. I do not want to cause an elderly and/or disabled person to lose their housing assistance, and then potentially their housing after that. However, if they are refusing all help, refusing they even need help and continuously come up with excuses as to why they cannot make changes. It's hard.

Another thing is HUD requires repairs/changes to be made within 30-days of the failed date. When I can, and the tenant ask for it I will give them a Reasonable Accommodation, however that usually is only an additional 30-days. I understand HD is not something that can be "fixed" in 30-days. That is why, when they are willing to get help and work on it, I am trying to find ways that extend it, with out being out of compliance with HUD.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

I would like more resources that can actually help them. There isn't a HD resource specifically that I can refer tenants to, in addition to the fact I cannot suggest a tenant has HD. There aren't any resources that will help them clean up/remove things with out a huge cost. Most people with HD are elderly and/or disabled and cannot afford anything that would cost them a lot of money. Because of this, even if they are willing to remove things, most of the time they are not physically able to do so. If there was an HD resource where people would help them with the actual mental disorder, as well as the physical aspect, at little/no cost or something that could bill their Medicare/Medicaid insurance, that is was is really needed.

Thank you,

Rebecca Poole

Rebecca Poole (She/Her/Hers)
HQS Support Technician
Housing Opportunities of SWWA
820 11th Ave
Longview WA 98632

Statement from Suzanne Norton, Social Worker, Jenks Center (Winchester, Massachusetts)

Submitted on March 22, 2024

1.How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

It has left them vulnerable and at greater risk of not being able to escape in the event of a fire. It poses as a fall risk. It puts them at risk for infestation of rodents and bugs. It is stressful and leaves them utterly unable to find important papers and forms that need to be completed in order to maintain housing and healthcare. It leaves seniors more isolated because they can't have people over without feeling ashamed of their home. There is no place for them to sit down. Often flies.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

I have spent hours, months, years trying to work with people to clean out their units with only temporary improvement. Because it's such a pervasive issue the behaviors just continue.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

we've helped secure funding for clean out services, dumpsters, even taken items out of home for donation- because people like the idea of giving them away to someone who could use them rather than just throwing them out.

It takes months and months of work and then it just doesn't seem to show lasting improvement, in most cases. I think people could use help with trash removal. Something as simple as someone picking up the garbage garbage. We try our best to find volunteers who are willing to help out. It is a big cost.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

Funds for clinical clean outs, organizational skill building, letting go, mental health support groups for hoarders, and funding for a task force for the Winchester, Burlington, Lexington, Medford, Arlington area. Trash Removal (as a prevention) Definitely mental health support services. There are usually compound variables that are at play where a person is stuck and needs a peer mentor for support as well.

Suzanne Norton

Social Worker | Jenks Center

Statement from Jewish Family & Children's Service of Greater Philadelphia

Jewish Family & Children's Service of Greater Philadelphia
Hoarding Support Program
Request For Information
April 15, 2024

1. **How has hoarding disorder impacted your community, particularly older adults and people with disabilities?**

The Jewish Family and Children's Service of Greater Philadelphia's (JFCS) Hoarding Support Program was developed in 2015 in response to a need identified by care managers serving older adults. The Mayo Clinic reports that hoarding tendencies tend to worsen with age and that the disorder is more common among older adults. Recent research further found that rates and severity of Hoarding Disorder increased as a direct result of the pandemic due to isolation related to mandated lockdowns and perceptions of scarcity that lead to panic-buying (Fontenelle et. al., 2021). Furthermore, hoarding disorders are on the rise due to an aging population and a national shortage of mental health care professionals in the wake of the pandemic. As the most developed hoarding treatment program with the highest intake capacity in the Philadelphia region, JFCS' specialized interventions are designed to address these challenges.

Hoarding Disorder is a complex mental disorder describing people who experience distress around discarding possessions and excessively acquiring new possessions. The accumulation of clutter impairs their day-to-day functions and threatens their quality of life. From JFCS' experience, we know clutter can prevent necessary service providers (exterminators, first responders, home cleaners, home repairs) from doing their jobs effectively. Clutter can lead neighbors or building managers to report these community members, which can lead to fines, evictions, or other court actions that could result in displacement or homelessness. Beyond the physical challenges associated with Hoarding Disorder, there are also social and emotional impacts.

JFCS understands the importance of data collection and analysis. We regularly evaluate client progress using internal and external measurement tools and client satisfaction surveys. We set clear program and individual goals and outcome targets and use Credible, a cloud-based behavioral health software, to collect, track, analyze, and report client and program data, activities, and impact. Specifically, JFCS uses the following assessment tools for our individual and group therapy services:

- Clutter Image Rating Scale (CIR), a tool used to gauge level of clutter; a score of four or higher would indicate Hoarding Disorder
- Activities of Daily Living – Hoarding (ADL-H), a tool to assess how daily functioning is impacted by clutter; a score of 1.5 or higher would indicate the need for increased support.
- Home Environment Index (HEI), a tool to assess for squalor in the home. This tool alone would not indicate hoarding but does assess for sanitary concerns in a hoarded home.

Jewish Family and Children's Service of Greater Philadelphia
The Barbara and Harvey Brodsky Enrichment Center
345 Montgomery Avenue | Bala Cynwyd, PA | 19004
T: 267.256.2100 | jfcsphilly.org
JFCS partners with the Jewish Federation of Greater Philadelphia

- Participants in the BIT curriculum support groups will complete pre- and post-program assessment tools to solicit feedback and evaluate progress on the Hoarding Rating Scale.
- Professionals and community members participating in group education/training will also receive post-training evaluations, including questions regarding whether they will use the information provided in their professional lives.

Over the course of the program, JFCS has achieved the following:

- 75.7% of clients showed improvement on the CIR
- 63.8% showed improvement on the ADL-H
- 68.6 showed improvement on the HEI
- 73.3% showed improvement on the BIT Hoarding Rating Scale

Approximately 2-6% of the population is struggling with hoarding disorder based on recent, albeit limited, research. Further demographics of those currently served through JFCS' program are: 5% are under age 50, 23% ages 50 to 64, 52% ages 65 to 79, 20% aged 80+, and 90% living at or below the Federal Poverty Level.

JFCS is part of the Philadelphia Hoarding Task Force (PHTF), through which we maintain a partnership with Pennsylvania Integrated Pest Management, National Association on Professional Organizing (NAPO), the local fire department, Department of Behavioral Health, and others. These partnerships are helpful in that we are able to extend our resources, discuss complex cases, refer to each other, and build relationships. The PHTF is widely known within the region's working groups and is often sought out for local counties and regions for insight into how to build a task force around hoarding disorder, needs and gaps in the community, service implementation, resource building, and more. The task force partners with prominent services with the Philadelphia area including Community Legal Services and CARIE (Center for Advocacy for the Rights and Interests of Elders).

Through the PHTF, JFCS connected with Daniel "Danny" Torrance who is the founder of DLT Decluttering. Danny continues to partner with JFCS by developing and facilitating Positive Psychology groups for those who hoard. Danny's groups are successful, well attended, and receive tremendous feedback. JFCS often looks to Danny for his expertise on Hoarding Disorder, and he remains a key stakeholder in the programming. Here is some direct feedback regarding his group:
"The Positive Psychology and Danny are BRILLIANT!!! I can not say enough about the GOOD and POSITIVE reinforcement that the classes have given me, and that is not even "scratching the surface" of my learning or understanding of the material! I definitely hope that I am able to attend the next co-hort(S)!"

JFCS is also a member of the national Network of Hoarding Professionals (NHP). Through NHP, we have connected with agencies across the country working to address hoarding with whom we can discuss challenges in hoarding treatment, potential funding sources, and strategies for approaching hoarding through a mental health framework.

Other partnerships include Mutual Support Consulting, where we have worked with Lee Shuer for a number of years and are now jointly developing a training hoarding disorder intervention certification intended for peer supports.

2. **How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?**

JFCS' role in the space is evolving; we are currently one of the only providers treating hoarding disorders utilizing a community-based approach in the Philadelphia region. In the past few years, JFCS has been working alongside the Philadelphia Hoarding Task Force (PHTF) to create a Medicaid reimbursable supplemental service through the Behavioral Health Managed Care Organization in Philadelphia County, Community Behavioral Health (CBH). This past summer, we were successful in our proposal being accepted; JFCS is now officially enrolled as a provider. Today, JFCS's hoarding treatment and therapy program is the most developed in the Philadelphia region and has the highest intake capacity, serving 65 clients annually.

JFCS offers many services including older adult case management, where social workers provide in home support to seniors to support them aging in place with dignity. Often, hoarding disorder is found during home visits and is a barrier to individuals remaining in their home safely. The addition of our Hoarding Support Program has been instrumental in providing appropriate, trauma informed support and care.

3. **How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?**

Each year, JFCS' Hoarding Disorder program supports approximately 75 clients to help them reduce the negative impacts of hoarding behaviors and create stability in their home environments. JFCS care managers develop individual care plans, monitor client progress towards long-term goals and safety, and reduce recidivism of hoarding behaviors with added support provided by a certified peer with lived experience. Most services are provided in the individual's home, and visits will be scaled back when determined that the home is safe and behaviors are under control. Hoarding Disorder clients will also have access to support groups using the evidence-based Buried In Treasure (BIT) curriculum, and positive psychology groups.

JFCS' Hoarding Support Program focuses on a 4-tiered approach to help individuals first obtain safety in their home, reduce acquiring, increase discarding, and then learn organizational tools and skills to prevent clutter from returning. The 4 tiers are outlined as such:

- Ensure clients' safety in accordance with Philadelphia fire safety and building codes
- Support clients in reverting rooms in their homes to their intended function
- Establish organizational systems with clients
- Provide clients with after-care and continued care coordination to prevent relapse

JFCS has always had more referrals for our program than our staff capacity, and becoming a member of CBH has increased those referrals and will therefore allow us to hire new staff in the near future. The need for increased Hoarding Disorder services is not limited to Philadelphia County. JFCS is also in conversation with Magellan Behavioral Health of Pennsylvania, a behavior health provider in the region, to potentially expand services to Bucks and Montgomery Counties in 2025.

The increase in need is abundant; we welcome new clients and have identified the need to respond with more immediacy to begin building rapport and trust. Often, when a first responder, mobile crisis team, or other enforcement agency encounters someone who is hoarding, it can be a scary experience for the individual. The individual may not have received interventions or appropriate support in the past, leading to a lack of trust, shame, and fear of consequences. Many times, enforcement agencies or services identify those with hoarding disorder first and are not aware of any resources, available services, or most important – appropriate services to intervene. That leaves these individuals facing traumatic interventions such as forced clean outs, evictions, fear of losing their home, fines, and more. Given that Hoarding Disorder is a mental health diagnosis, it should be treated as such.

In the coming year, JFCS proposes adding a community outreach worker to our team who could respond sooner and begin engaging individuals in services, working directly with the enforcement and mental health service providers as a warm handoff. Our goal is to increase trust, engagement, and rapport so those struggling with Hoarding Disorder are willing to participate in services that are appropriate and from a mental health lens. Providing timely care to clients with Hoarding Disorder is paramount to success, and this addition to our team will allow us to reach these clients with immediacy.

Our organization has faced challenges with helping external organizations, landlords, enforcement services understand the nuance of those with hoarding disorder and the treatment process. Our program and staff provide a lot of education and advocacy around this in hopes of leading to better outcomes for everyone. Often, hoarding disorder is identified in older adults meaning the level of clutter is higher, physical limitations may be a factor in reducing clutter, and this can lead to a slower treatment process. Many clients we work with have faced clean outs or other shame inducing interventions prior to working with us, leading to more fear and uncertainty in reaching out and engaging in the process. While, we are able to overcome these challenges they do run the risk of increasing the time it takes to help someone return their home to a place that is safe and sanitary. Finally, the biggest challenge is the

need far exceeds our program's capacity at this time and a lot more growth and funding to grow is needed.

4. **How can the federal government help your organization assist older adults and others with hoarding disorder? If feasible, please share data and primary source information related to the rate and impact of HD on your organization and community.**

The federal government can support our organization and region by supporting the need for more data and information to be collected and accessed. There is limited data available on hoarding disorder in our region, none that is formally collected, nor the financial impact of hoarding on the community. The costs are substantial when considering the cost of evicting those who may be elderly, impoverished, or generally speaking more vulnerable populations and the cost of rehabbing the unit or residence; finding new housing options for those who are evicted; the cost of emergency personnel who are supporting or risking safety by entering hoarded homes; inability to return home from hospitalizations or rehabilitation centers due to safety concerns in hoarded homes; to name a few. Having a broader understanding of the need and cost of hoarding disorder will broaden our ability to build more programming and services to treat this complex disorder and increasing resources for community providers, emergency personnel, family members, individuals, and others to have access to care.

Statement from Kerri Anzulewicz, Assistant Director, Lackawanna County Area Agency on Aging (Pennsylvania)

Submitted on April 4, 2024

Survey Questions:

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?
    - Those with HDs are often at risk for housing instability due to condemnation or eviction. Limited affordable housing, coupled with the barriers an eviction brings to the table, increase the risk of premature placement or homelessness.
    - Those with HDs often refuse to allow services in the home, such has home health care, personal care aides, home maintenance. Often times these professionals refuse to go into a home wherein hoarding exists due to safety hazards and inability to access areas to allow tasks to be completed.
    - These individuals are at greater risk for social isolation due to not allowing others in their home and their inability to leave their residences.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?
    - There is a lack of resources to respond to hoarding. The intensive in-home therapy that is needed to facilitate improvement in someone with a HD is difficult to find or non-existent in our area. Identifying a provider for this type of therapy is a barrier but additionally identifying a payor for this therapy is an issue.
    - While we as an Area Agency on Aging can at times justify a cleaning service to resolve an immediate threat of eviction, the cleaning services that exist and are affordable are simply going to gather and discard of the collected items. This method is often refused by the individual and, when consented to, can further trauma impacting the individual.

3. How has your organization responded to hoarding disorder, including establishing new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?
    - We have engaged with family and informal supports to address hoarding issues. Individuals with a HD often will not agree to any intervention offered and only become agreeable when there is a threat of eviction. We try to work with informal supports to develop a plan that is less traumatic. We encourage the individual to participate in counseling.

If we agree to pay for "junk" removal the individual has to sign consent and agree to counseling through one of the area providers. This counseling is not in-person and in-home.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?
    - Encourage and require insurance companies to pay for the level of counseling or therapy these individual need.
    - Encourage and develop pathways (maybe grants or incentives) for providers to develop hoarding specific programing i, n-person/in-home support for these individuals, support groups, etc

Kerri Anzulewicz

Assistant Director
Lackawanna County Dept. of Human Services
Area Agency on Aging
123 Wyoming Ave. Scranton PA 18503

Statement from Emily Bremer-Thomas, Adult and Aging Supervisor, Loudoun County, Virginia

Submitted on April 3, 2024

Dear Senate Special Committee on Aging,

Thank you for interest in hoarding and its impacts on older adults and people with disabilities. Below please find the responses for our agency.

1) How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

The Adult and Aging program frequently receives reports of concern for older and/or disabled adults with hoarding disorder. Hoarding is often only one of the issues the adult is experiencing, and the hoarding can be a barrier for the adult to access other services. For instance, it can be difficult to find a home health agency or skilled services provider such as physical therapy to agree to come into the home. Additionally, it increases the isolation of older adults because they do not want other people to come into their home and see the hoarding I. solation is a significant contributing facto tr o an adult's risk of abuse, neglect/self-neglect and exploitation.

Hoarding increases health and safety risks for adults due to the exposure to hazards such as mold, dust, exposed garbage, and animal feces. The cluttered environment also creates a risk of falls and difficulties for an adult to exit the home in an emergency or for emergency services workers to gain entry to the home. As the condition of the home deteriorates due to hoarding, the adult becomes at risk of homelessness due to either being evicted or the home being condemned.

2) How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

It is difficult for our organization to serve adults with hoarding disorder due to the complexity of the issue and limited resources. It can be challenging to even get an adult with hoarding disorder to speak to us or let us in the home to discuss services. If an adult is willing to address the hoarding there are limited resources available in the community and are often expensive. The adult typically is unable to afford to pay for services on their own.

3) How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

Our organization has partnered with other agencies such as Habitat for Humanity and mental health services to jointly address the issues in the home and help the individual. A hoarding task force with multiple community partners such as Adult Protective Services, the Fire Marshal, the Health Department and Animal Services was created to address hoarding in the community. There is an online database that allows community members to submit suspected hoarding cases to the county. The taskforce has faced difficulties in being successful due to the limited resources available as well as an adult's willingness to address the hoarding. There are significant difficulties in getting adults to consent to decluttering services or to engage with mental health services to address the root cause of hoarding.

4) How can the federal government help your organization assist older adults and others with hoarding disorder?

Provide funding for hoarding services such as decluttering, support groups, awareness campaigns, and partnerships for social services, mental health and other stakeholders to respond jointly.

Thank you for your time and consideration of this matter,

Emily Bremer-Thomas
Adult and Aging Supervisor
102 Heritage Way NE
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Leesburg, VA 20177

Statement from Massachusetts Older Adult Behavioral Health Network and Massachusetts Hoarding Resource Network

April 15, 2024

To the Senate Special Committee on Aging,

Thank you for this opportunity to provide information on the impact of the lack of services and treatment for hoarding disorder and recommendations to help people who are at risk of costly nursing home admissions and homelessness live healthy lives in the community. I am a former Elder Protective Services Worker, current social worker in a Massachusetts-based Elder Mental Health Outreach Team (EMHOT), and chair of the Massachusetts Older Adult Behavioral Health Network and Massachusetts Hoarding Resource Network (MHRN). I am pleased to provide this feedback based on my experiences, in collaboration with the MHRN Steering Committee.

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Before working in Elder Protective Services, I assumed, like many people, that hoarding was not a common occurrence. Because hoarding occurs behind closed doors and is associated with isolation, it is a hidden problem with higher prevalence than people might think. It is also one that lacks a coordinated response by communities and effective available treatment. Research demonstrates that hoarding can be treated; however, more resources are needed to advance treatment and to train providers so that people have access to the support they need.

The lack of specialized treatment is compounded for older adults, who face age-related barriers to mental health treatment including the cost of co-pays, lack of transportation, mobility impairment, ageism among providers, stigma associated with mental health, and co-occurring cognitive conditions that can result in difficulty scheduling appointments. Due to barriers such as these, they are the least likely of any age group to receive mental health treatment.[1]

For older adults in rental and particularly subsidized housing, hoarding poses a risk for homelessness. Invisible disabilities, such as mental health conditions, are frequently overlooked and misunderstood, particularly as they pertain to housing rights. It is easy for people to identify the need for a physical reasonable accommodation (i.e., a ramp), but it can be more challenging for providers to understand how to develop accommodations to help an individual at risk of housing loss due to a hoarding condition. Such an accommodation could include treatment paired with inspection schedules to monitor progress in lieu of moving forward with eviction. However, the effectiveness of such accommodations to support people

[1] Elshaikh, U., Sheik, R., Saeed, R. K. M., Chivese, T., & Alsayed Hassan, D. (2023). Barriers and facilitators of older adults for professional mental health help-seeking: a systematic review. *BMC geriatrics*, *23*(1), 516. https://doi.org/10.1186/s12877-023-04229-x.

with hoarding conditions to live in the community are reliant upon the availability of treatment and services.

Housing managers have a difficult job, as hoarding in one unit can impact an entire apartment complex due to spread of infestation or fire hazards. Stigma, lack of coordinated response teams, and lack of available treatment means that people often do not receive treatment until there is a crisis, at which point it is much more difficult to help. Crises such as an immediate risk of eviction or home condemnation, a fire, or an injury due to safety hazards in the home are detrimental to individuals, their families, neighbors, and the community at large.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Older adults with hoarding conditions are frequently referred, at the point of crisis, to Elder Protective Services. Often, they are unable to safely be discharged home from the hospital due to lack of suitability of the home for visiting nurse and other homecare services -- or they refuse these services and postpone critical medical care due to shame associated with the condition of the home.

Responding to crisis situations results in unnecessary expenditures of time and money that drain an already stretched thin workforce and ultimately do not best support people who are at risk due to an untreated hoarding condition. The lack of available treatment -- specifically in-home occupational therapy, cognitive behavioral therapy for hoarding and trained professionals to support sorting and discarding -- means a "revolving door" where individuals are chronically at risk.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

The MA Statewide Hoarding Steering Committee was formed in 2007 by professionals from multiple disciplines including housing, health, public safety, code enforcement, human services, and academia to learn about hoarding and work together towards solutions, increased education, and better service and treatment coordination. Some of the achievements of this group include:

- The development and support of trainings and conferences for front-line housing and social services staff
- Led by the Boston University School of Social Work, the development and implementation of HOMES®, an interdisciplinary Risk Assessment that can be used by all parties to help assess and plan.
- The establishment and updating of a Massachusetts-focused hoarding website at www.masshousing.com/hoarding which includes posts for community events, training opportunities, information, tools, and resources.

- Pilot-program funding for therapeutic in-home sorting and discarding services to nineteen households in FY12-13 and another program funding hoarding assistance to thirty-four MassHousing sites through that agency's Tenancy Preservation Program in FY15-19.
- The provision of technical assistance to emerging regional and local Hoarding Task Forces. (Seven existed in 2007; over twenty in 2019)
- Sixty-one grants to 21 MA Local Hoarding Task Forces in FY15-FY19 that have sponsored hundreds of professional and peer-led support groups, community events and trainings, and direct case interventions/services.
- Completion of the Hoarding Survey and Summary Report.

Additional achievements in Massachusetts include the establishment of Elder Mental Health Outreach Teams (EMHOTs) under the Executive Office of Elder Affairs. EMHOTs provide in-home short-term counseling, crisis intervention, case management, and referrals for older adults with mental health conditions, including people with Hoarding Disorder. Massachusetts also has a large number of trained Buried in Treasures facilitators. These facilitators lead decluttering support groups at local senior centers.

The MA Statewide Hoarding Steering Committee was relaunched as the MA Hoarding Resource Network in Fall 2023 after a hiatus during the pandemic.

4. **How can the federal government help your organization assist older adults and others with hoarding disorder?**

    - Define Hoarding Disorder as a serious mental illness and allocate SAMSHA funding, research, and resources to help people at risk of homelessness due to Hoarding Disorder.

    - Provide funding to states for the development of state and/or regional Hoarding Resource Networks to support state program development.

    - Provide funding opportunities for Hoarding Disorder first response and housing stabilization teams. Teams should incorporate aging and behavioral health services, occupational therapy, police and fire departments, legal services, cleaning and inspectional services.

    - Support states with the broader goal of integrating aging and behavioral health services, including grant funding for in-home behavioral health care delivery models. This could include integrated and wrap around Collaborative Agreement Models such as:

        - Behavioral Health, Home Care, and Adult Protective Service Agencies interagency agreement models for integrated or wrap around services

    - Certified Community Behavioral Health Clinics (CCBHC) guidance on interdisciplinary Hoarding Disorder treatment including PSS and CHW services.
    - CBHC model development that engages Designative Collaborating Organizations (DCOs) currently providing older adult and individuals with disabilities support service (such as Adult Protective Service Community Providers, Long Term Services and Support (LTSS) Agencies, and Home Care Agencies) to fill service gaps for older adults and individuals with disabilities, particularly for treatment of Hoarding Disorder.
    - CCBHC guidance in clinical services and integrating Peer Support Groups and PSS and CHW specialized services for older adults and individuals with disabilities, particularly for treatment of Hoarding Disorder.

- Build on the new opportunity for Medicare funding for PSS and CHW services to Medicare recipients by providing federal government funding for states to build this workforce for the older adult population, particularly for individuals with Hoarding Disorder through:
    - Further Medicare reform to expand the scope of PSS and CHW services to include "light home clean-out services and trash removal" for individuals with HD.
    - Federal grants to states to develop an older adult PSS and CHW workforce
    - PSS & CHW training in Hoarding Disorder support services, including in home coaching and "specialized light clean-out assistance and trash removal services."

- Provide funding for the development of a national repository of nonproprietary and editable HD training in service topic areas such as:
    - Approaches to psychiatric and therapeutic interventions, including:
        - Medication treatment
        - Motivational Interviewing (MI)
        - Cognitive Behavioral Therapy (CBT)
        - Exposure Therapy with Response Prevention (ERP) for reducing acquisitions.
        - Compassion Focused Therapy (CFT)
        - Acceptance and Commitment Therapy (ACT)
        - Integration with Peer Support Groups
    - Support service workforce
    - Safety and harm reduction
    - Light and heavy clean-out workforce
    - Legal system advocacy and services to supports rights to accommodation plans for invisible disabilities like HD and other mental health conditions.
    - Housing and public safety

Thank you for this opportunity to comment. Please let us know if there is any way that we can support your efforts.

Sincerely,

Cassie Cramer, LICSW
Project Manager, Older Adult Behavioral Health Network
[redacted]

and the Massachusetts Hoarding Resource Network Steering Committee:

David Eng, Housing Stability Specialist
Mass Housing
[redacted]

Lee Shuer, CPS, President
Mutual Support Consulting, LLC
[redacted]

Erika Woods, MS, RS, Deputy Director, Health and Environment
Barnstable County, Regional Government of Cape Cod
https://www.capecod.gov/departments/cape-cod-hoarding-resource-network/
[redacted]

Statement from Christine Willander, Mashpee Massachusetts Board of Health

Submitted on March 25, 2024

Please see responses to your questions:

How has HD impacted our community, particularly older adults and people with disabilities?

As a Health Department, we see the number of moderate to advanced hoarding cases increasing at an alarming rate. In most cases, we are alerted to these situations by first responders who report unsafe/unsanitary conditions within a dwelling. More often than not, the occupant is an older adult; however, we also see HD among young and middle-aged adults, including those with anxiety/depression and substance use issues. In terms of its impact on the community, we as a health department receive frequent complaints from abutters/neighbors who are concerned about property values and the aesthetics of the neighborhood. Neighbors will also contact us with reports of rodent sightings at properties where HD is often the source.

How has hoarding disorder impacted our organization, particularly in its ability to carry out its mission?

Trying to enforce the Sanitary Code and Nuisance Laws in these situations, without the assistance of a mental health professional, is counter-intuitive and creates stress, frustration, and discouragement among health inspectors. We are typically unsuccessful in effecting compliance with respect to any related violations, due to the fact that that we are not equipped with the necessary skills/credentials to address the underlying mental health issue.

How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

Valuable time and resources are expended investigating complaints, networking, researching referrals, and taking enforcement action. Barnstable County has recently re-booted its Hoarding Resource Network, but not enough time has passed to assess its efficacy.

How can the federal government help your organization assist older adults and others with hoarding disorders?

Dedicated mental health professionals who can review and advise local health inspectors on complex cases; *training for local health inspectors; funding for dumpsters and clean-up services; more local programs such as "Buried in Treasures" w/ online options and/or transportation assistance.*

Thank you.

Christine A. Willander | Assistant Health Agent
Board of Health

Statement from Sandra Swogger, Chief Executive Officer, Mercer County Area Agency on Aging, Inc. (Pennsylvania)

Submitted on April 2, 2024

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?
    - People with hoarding disorder risk losing their homes. Code enforcement officers will demand the hoarders clean up the property or else the property will be condemned and the residents have to vacate. The properties are often torn down and the resident has no place to go.
    - When hoarders are asked to leave a property, they often start all over again, hoarding the new residence and the cycle repeats.
    - We have found that often the hoarded home is infested with rats, bedbugs, insects, creating health hazards for the resident(s) and concerns from neighbors.
    - Black mold is also often found in the home of a hoarder creating a serious lung infection of the resident(s).
    - Rotting food and paper and garbage will destroy walls and floors, creating a serious safety hazard.
    - Safe movement in the home is often an issue. Emergency personnel cannot get to a person in distress because of the blocked pathways and often the hoarder is climbing over debris to get to the door, which takes time which could be dangerous.
    - The hoarder risks the piles of debris falling down upon them, burying them with no ability to call for help.
    - The hoarder will often lose family ties, so families are reluctant to assist with personal care needs.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?
    - Our mission is to advocate for the older adult, assisting them to live where and as they choose for as long as possible. Often, in a hoarding situation, there is very little we can do to assist the person to stay where they are and to stay safe.
    - Although a hoarder has a mental health issue, if they are over the age of 60, there is no help for them. Mental health services are difficult to secure for someone over the age of 60, and without the counseling needed to help the hoarder, the hoarding will persist.
    - Cleaning out hoarded homes is costly and our current funding is not sufficient to assist with removing the debris from inside and/or outside the home.

- Family members absolve themselves from the hoarder due to embarrassment, frustration, and exhaustion trying to deal with the problem.
- Landlords are reluctant to take in someone known to be a hoarder because of the destruction it can do to a home, making placement a very difficult task.
- Hoarders refuse to believe there is a problem and often will refuse help of any kind, creating a very adversarial relationship.
- Staff becomes frustrated when they attempt to assist but because a person has a right to live as they choose, even though we may see them as making bad choices, our hands are tied. We cannot intercede if the person refuses our assistance, unless they are determined to be incapacitated. Then an emergency hearing with the Courts may be necessary to remove the person from the risk. This takes time and can be very costly.

3. How has your organization responded to hoarding disorder, including establishing new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?
    - We have formed relationships with local code officers, city officials and law enforcement.
    - We have reached out to form partnerships with local human service and health-related organizations to work on developing a plan of action to deal with hoarding situations.
    - We have found a local mental health organization that has staff who work with hoarders, however the staff will not go out into the community, but the hoarder must go to the staff person's office. We are unsure of the validity of the service if the staff cannot go to the home. The hoarder often does not think they need help.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?
    - Provide payment to mental health providers to go into the community, meet the hoarder where they are and get the hoarder the mental health treatment they need.
    - Create a special unit to combat issues surrounding hoarding.
    - Fund special training for mental health workers to be certified counselors for hoarding disorder.

Sandra Swogger, *Chief Executive Officer*
Mercer County Area Agency on Aging, Inc.
133 N. Pitt Street, Mercer, PA 16137

Statement from Old Colony Elder Services (OCES)

1. How has hoarding disorder impacted your community, particularly older adults, and people with disabilities?

   Old Colony Elder Services (OCES) is the designated Aging Services Access Point (ASAP) for 23 communities in greater Plymouth County. With 50 years of experience coordinating in-home services and supports for older adults and individuals with disabilities, OCES found that the need for hoarding disorder and excessive cluttering services was essential to the safety and well-being of the consumer we served. Beginning in 2011 OCES begun working with consumers, community entities, public service providers, and other OCES programs with the inception of the Greater Brockton Area Hoarding Resource Network (GBAH). Since then, in a variety of ways, OCES has received hundreds and hundreds of calls from family members and professionals with information on hoarding disorder, direct one-on-one services, professional developments, and group format. If we receive a call, email, or referral we respond, to help provide resources to assist regarding hoarding. Currently we have a waitlist of 18 consumers who need one-on-one services and 23 professionals who are interested in professional education and training on hoarding disorder, and we receive ongoing inquires and referrals for hoarding disorder weekly.

   Through working directly with consumers one-on one in their homes and in group format, OCES has seen first-hand how hoarding disorder affects our consumers' safety and well-being. Consequences of hoarding disorder has caused extreme stress in consumers causing mental health crisis' especially in circumstances where forced clean outs are mandated or performed without consumers' participation. These types of clean outs are usually completed by the Board of Health and Housing Authorities when the consumer has not been responsive to their request to adhere to the lease or city/town sanitary code. These circumstances have left consumers homeless or caused loss of housing vouchers/section 8 due to eviction. These consumers are usually reported to Adult Protective Services or other services such as Tenancy Preservation or our OCES' Behavioral Health team. However, affordable one on one resources are not commonly available to assist consumers in their home. Furthermore, clean-outs done correctly take a long time as it requires sorting and processing their items and exploring the underlying cause of hoarding disorder. Through published research and through direct work with consumers, hoarding disorder can also cause isolation from friends and family due to embarrassment and shame, as well as a higher risk of medical issues. Per Blazer 2020, isolation puts older adults and people with disabilities at a 50% increase of developing dementia, 30% increased risk of coronary artery disease or stroke, and 26% increased risk of overall morality. In addition, safety risks are high for this population as hording increases the risk of falls, infestations, fire, and avalanches of items which increased risk of being buried among items if they should fall.

   Hoarding clean outs of any size are costly. Seeking home insurance assistance is tricky as there is an increased risk of insurance companies cancelling an individual's insurance if they are aware that hoarding is an issue and often times, necessary

repairs are not approved if the issue is due to hoarding. In most situations, the home insurance companies won't pay for cleaning and home repairs as they deem the situation neglectful of owners. In some situations, the home insurance company have dropped the consumer's home insurance and "blacklisted" their name and property. This causes the consumer to be left without house insurance, or required to fix issues in home before current insurance company will renew policy in addition to raising cost of insurance due to risks.

2. We have worked with consumers, that do not understand their circumstances or what hoarding disorder is or why it is an issue due to lack of insight. Lack of insight may be caused by many factors but most commonly due to emotional attachments and belief systems; cognitive processing issues such as ADHD, and positive reinforcements of negative behaviors. Overall, these situations have impacted our consumers by increasing mental health and medical conditions, loss of affordable and safe housing, financial burden, and safety issues. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

   OCES' mission supports the independence and dignity of older adults and individuals with disabilities by providing essential information and services that promote healthy, safe living which positively impacts our community.

   In order to support our mission and consumers, OCES has had to pivot and develop resources to support consumers and others in our community. OCES now offers community education and supports as well as individual one-on-one services for our consumers. As stated earlier, OCES established the Greater Brockton Area Hoarding Task Force, now known as the Greater Brockton Area Hoarding Resource Network. The name change signifies one of the advancements in the field by reducing stigma attached to hoarding disorder by the use of language. For example, by changing the name from taskforce to resource network, we are acknowledging the need for continuous supportive service and resources in the recovery process vs. a onetime task to alleviate issue. The term task force took on a punitive tone and gave people the impression that there could be a use of force, which wasn't what the network wanted for our consumers.

   The Resource Network meets bi-monthly and shares information about hoarding disorder and best practices in the field. OCES has provided several trainings on Hoarding Disorder to support first responders and other professionals, caregivers, family and friends of individuals that are dealing with hoarding. This education is especially important for first responders as they are the ones who are most likely to identify consumers who are affected by hoarding in the community. The goals of these educational events include educating them on hoarding disorder, identifying the best way to work with the individual and to overall determine if the individual is dealing with hoarding disorder or the inability to physically clean out their space or perhaps the situation is due to medical reasons or another metal health disorder. However, it is important to reiterate that even with these trainings, the cost of clean outs and lack of hoarding disorder clinicians and services that are able to work with consumers limits the impact that can be made in the community. This has required OCES to invest finances and staff time to support those in need. OCES has an ongoing waitlist for hoarding disorder services and supports. Currently, we have a waitlist of 18 older

adults and 20 professionals. Additional funding to hire trained staff and assist with high cost of clean outs is needed to serve the individuals living with hoarding disorder.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

As stated above, OCES created a Resource Network of professionals to share information and educate the public on hoarding disorder. OCES offers the following:

1. A coaching program that assists OCES consumers in their home who are at risk of eviction due to hoarding disorder. The option to utilize this program is limited due to funding which affects staffing ability, hands on services, and house maintenance that needs to be completed.
2. A 16-week clinician lead Buried in Treasures Workshop at least once a year when funding is available to support individuals who are dealing with hoarding tendencies. This program supports 8-10 people yearly and does not include in-home assistance.
3. When funding is available, OCES and Greater Brockton Hoarding Resource Center can sponsor a Buried in Treasures facilitator training for 10 professionals to become professionally trained to facilitate Buried in Treasures Workshops. This training allowed 10 professionals and peer volunteers to hold the workshops.

How can the federal government help your organization assist older adults and others with hoarding disorder? If feasible, please share data and primary source information related to the rate and impact of HD on your organization and community.

The Federal Government can help our organization assist older adults and others with hoarding disorder by:

1. Provide federal acknowledgment and education of hoarding disorder, and funding for clean out services for those who are working with a coach;
2. Provide funding to hire staff to clinically coach and/or provide therapy for consumers during clean outs;
3. Provide legislation or authorization for health insurance companies to reimburse clinicians for therapy/clean outs;
4. Provide legislation or authorization making clean outs and/or housing repairs an authorized use of homeowners insurance funds and furthermore, ensure that consumers are protected when accessing such funds so they cannot be "black listed" or incur financial penalties when renewing homeowners insurance;

Citation

Donovan NJ, Blazer D. Social Isolation and Loneliness in Older Adults: Review and Commentary of a National Academies Report. Am J Geriatric Psychiatry. 2020 Dec;28(12):1233-1244. doi: 10.1016/j.jagp.2020.08.005. Epub 2020 Aug 19. PMID: 32919873; PMCID: PMC7437541.

Statement from Rhode Island Hoarding Taskforce

RHODE ISLAND
Hoarding Task Force

April 12, 2024

The Rhode Island Hoarding Taskforce is eager to support the work of the Senate Special Committee on Aging in addressing the needs of Individuals with Disabilities and Older Adults with Hoarding Disorders. We appreciate the opportunity to provide comments and are looking forward to the Committee's efforts to assist individuals with hoarding disorders. Additionally, our statewide Rhode Island Task Force is encouraging members to provide their perspectives for continued advocacy to highlight unique community service needs impacting our Rhode Island communities.

1. **How has hoarding disorder (HD) impacted your community, particularly older adults and people with disabilities?**

The prolonged workforce shortage and financial strains of the healthcare industry has intensified the unmet needs of the behavioral health provider and social service support community servicing individuals with HD. Particularly, the lack of resources for sufficient specialized HD training and HD program development has further impacted the ability to address the emotional health and safety needs of individuals with HD, particularly for older adults. The needs of individuals with late life hoarding associated with cognitive deficits including decision making and executive functioning has been further exacerbated by the increased incidences of loneliness and social isolation of older adults living in the community.

Hoarding disorder can meet criteria for serious mental illness (SMI) and often requires access to intensive long-term community support services. The housing shortages, the lack of behavioral health, levels of care beds, and nursing facility financial and staffing challenges has resulted in an increased in evictions and homelessness for individuals with hoarding issues. The state agencies that operate Protective Services Case Management programs have seen a substantial increase in those facing hoarding challenges. The cases that are being reported are exceeding the resources the state has available. With every case being so unique we have realized there is no one size fits all model that can be implemented. Within these programs our community has seen an increase in home hazards that have led to hospitalizations, isolation, and evictions. These challenges and the lack of funding make it difficult for individuals with hoarding disorders to access the full continuum of supports and care across living settings.

2. **How has hoarding disorder impacted your organization, particular in its ability to carry out its mission?**

The diminished workforce has resulted in expanded caseloads and reduced access to prevention services. An increase in the demand for acute and crisis management services, thereby reduces availability to engage in non-direct care work, such as participating in Hoarding Task Force activities. The State Task Force is also receiving an increase in request for individual case assistance, further reducing the ability to carry out its mission to engage in activities to support community program development.

3. **How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?**

Our community engagement activities repeatedly highlight local needs for behavioral health, social service, legal and clean out workforce program development to address the needs of older adults and the community impacted by hoarding. Across Rhode Island the behavioral health workforce has recognized this gap and requested expanded HD training resources.

Furthermore, our State Aging Department's Protective service program's members have seen an increase in the demand for services resulting in an underfunded mandate. Requests for prevention services, case management, home care, Long-Term Services and Support (LTSS) services, behavioral health treatment and crisis services targeting older adults have increased and are not sufficient to meet the HD population needs. When specialized HD long term services are not available to address the long-term needs for individuals with HD and related conditions, Adult Protective Services cases get closed due to lack of engagement support through access to supplemental HD services. Sometimes both new and these closed cases, ultimately result in the protective service worker getting called into crisis management for extreme safety issues where the financial and legal resources may not be able to mitigate extreme situations that have developed over a long period of time.

Providing opportunities for funding that increases State resources for HD program development can help reduce the need for protective services and help keep individuals with HD and related conditions stay in their homes. Combining clinical and social supports with a range of outreach and early intervention services, home stabilization services, housing eviction prevention services that address mild to moderate safety issues; can prevent eviction, housing displacement, and improve the quality of life for individuals with HD.

Presently, the RI Hoarding Task Force, convened under the RI Elder Mental Health and Addiction Coalition, has attempted to address the needs of Rhode Islander's impacted by HD and related conditions through a focusing on:

- Website Resource Development.
- HD Workforce Training in areas such as (a) Buried in Treasures (BIT) program development (b) Eviction, Safety and Harm Reduction Training and (c) Subsidized Housing outreach, and (d) Community Collaboration in Hoarding Services.
- Workforce Support Sessions.
- Community Engagement and Partnership Development.

More effort is needed. With additional supports, Rhode Island can better address the needs of individuals with HD.

4. **How can the federal government help your organization assist older adults and others with hoarding disorder?**

The federal government could assist older adults and others with hoarding disorder through:

- Further Medicare reform to expand the scope of Peer Support Specialist (PSS) and Community Health Workers (CHW) services to include "light home clean-out services and trash removal" for individuals with HD.

- In February 2024, Medicare announced new opportunity for Medicare funding Peer Support Specialist and Community Health Workers Services to Medicare Recipients. (See: https://www.cms.gov/newsroom/fact-sheets/calendar-year-cy-2024-medicare-physician-fee-schedule-final-rule; https://www.commonwealthfund.org/blog/2024/medicare-reforms-support-behavioral-health-expanding-access-peer-support-specialists-and).

    - However, federal government assistance is needed for states to build this workforce for the older adult population, particularly for individuals with HD.

    - The Federal Government's assistance for PSS and CHW Specialized Workforce Training for HD provides opportunity for sustainability of a workforce development initiative to address gaps in HD services for Older Adults and individuals with disabilities, where a majority are on Medicare.

- Federal state grants to states for PSS and CHW servicing older adults & individuals with disabilities for expanding:

    - Peer Support Specialist (PSS) workforce servicing older adults & individuals with disabilities.
    - Community Health Worker (CHW) workforce servicing older adults & individuals with disabilities.
    - PSS & CHW trained in HD support services.
    - PSS & CHW trained in "specialized light clean-out assistance and trash removal services".
    - Streamlined state PRS and CHW Certification Process and Co-Certification Career ladder funding.

- Funding development of a national repository of nonproprietary, and editable HD training in service topic areas such as:

    - First responders
    - Specialized BH counselors in areas such as:
        - Medications treatment
        - Safety and Harm Reduction
        - Motivational Interviewing (MI)
        - Cognitive Behavioral Therapy (CBT)
        - Exposure Therapy with Response Prevention (ERP) for reducing acquisitions.
        - Compassion Focused Therapy (CFT)
        - Acceptance and Commitment Therapy (ACT)
        - Integration with Peer Support Groups
    - Support service workforce.
    - Light and heavy clean-out workforce.
    - Legal system advocacy and services to supports rights to accommodation plans for disabilities.
    - Housing & public safety
    - Certified Community Behavioral Health Clinics (CCBHC) guidance in clinical services and integrating Peer Support Groups and PSS and CHW specialized services for older adults and individuals with disabilities, particularly for treatment of HD.
    - Integrated and wrap around Collaborative Agreement Models such as:

        - Behavioral Health, Home Care, Adult Protective Service Agencies Interagency agreement models for integrated or wrap around PSS & CHW services.
        - Certified Community Behavioral Health Clinics (CCBHC) guidance on interdisciplinary HD treatment including PSS and CHW services.
        - CCBHC model development that engages Designative Collaborating Organizations (DCO) currently providing older adult and individuals with disabilities support service such as Adult Protective Service Community Providers, Long Term Services and Support (LTSS) Agencies and Home Care Agencies to fill service gaps for older adults and individuals with disabilities, particularly for treatment of HD.

- Funding grants to state for the development of State or Regional Hoarding Taskforce Advisory and Planning Committees to support state program development to include task such as:

    - Person-centered programing tailored to state specific strengths and needs.
    - Identify issues that drive/impede service access.
    - Propose solutions to increase service capacity.
    - Define roadmap for program implementation including steps to follow.
    - Define data points that can measure progress.

- Funding grants for the development of state or regional HD first response and early intervention interdisciplinary team services incorporating key state stakeholders such as State fire Marshall, State police, State Departments of Behavioral Health and State Department of Aging Crisis and Protective Services, State building inspector, State public housing office and Community behavioral health crisis and outreach staff.

- Funding to State grants for State Program Development that supports program development in areas such as:

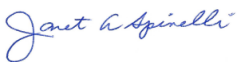
    - Streamlining co-certification for Peer Support Specialist Certification and Community Health Worker Certification
    - Support workforce career ladder such as funding increase for PSS and CHW co-certification(s) and delivery of specialty HD services.
    - Development of HD training for (a) Peer Support Specialists and Community Health Workers, (b) BH clinicians (c) Police, Fire, behavioral health, and community first responders.
    - Streamlining Medicaid provider application process
    - Education, Outreach and Training Development

- Incentive state grant funding targeting HD services for older adult population such as for:

    - Free Peer Support Specialist training and certification support to individuals who commit to work with older adults with HD on Medicaid and Medicare Insurance
    - Free Community Health Workers training and certification support to individuals who commit to working with older adults with HD on Medicare and Medicaid Insurance.

Once again thank you for the opportunity to respond to these important questions. Please let us know if you have any questions or request additional information.

Sincerely,



Janet A. Spinelli PhD, APRN, PMHCNS RI Hoarding Task Force Co-Chair

Kelly McHugh, RI Hoarding Task Force Co-Chair

The RI Hoarding Task Force

[redacted]

Statement from Jams Stuivenga, Clinical Supervisor, Sound Generations (Seattle, Washington)

Submitted on April 15, 2024

To the Members of the U.S. Senate Special Committee on Aging:

Sound Generations is a multiservice nonprofit organization partnering with older adults to remove the inequities that impact aging by providing accessible, essential and inclusive services that support people through their life's journey. We are located in Seattle, WA and serve diverse communities across King County. None of our programs diagnose or treat hoarding disorder as a behavioral health issue, so we have not collected data on the number of calls or cases that involve hoarding disorder as a primary or related issue. However, our staff are very familiar with the matter as it routinely factors in the need for services when staff provide resources, education, and referrals to individual clients and their support networks.

How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

One of Sound Generations' programs, Pathways Information & Assistance, gets many calls from families, professionals, and clients who need help with hoarding clean up and support but are unable to afford the cost of hiring someone. Often, the hoarding situation is a barrier to in-home care services, causes falls requiring emergency response j, eopardizes housing stability, decreases the overall well-being of those in the home (as well as neighbors in multi-unit buildings), and requires frequent service calls or welfare checks for non-emergency situations.

Another program, the Geriatric Regional Assessment Team, receives a couple of referrals per month for older adults with hoarding issues, which contribute to health and functioning issues, putting them at risk of a medical emergency or losing their housing. In responding to other referrals, the team regularly encounters older adults living in cluttered home environments but are limited to screening for hoarding disorder because corresponding services are largely unobtainable.

How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Sound Generations sometimes cannot serve clients that are living in unsafe environments. The clients miss out on delivered meals, transportation, and other services as staff cannot safely access the home or clients cannot get out of their homes. Separate from our services, we find a number of clients are unable to receive in-home Medicaid services because of the condition of their homes.

Often, Adult Protective Services are involved, but they have limited resources to connect people to support services.

How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges have your organization faced while implementing that response?

In the last year, Sound Generations was able to pilot a decluttering program with surplus funds from the County. The program was very popular, using up all time-limited funding provided within three months. owever, this program was intended for older adults who did not need behavioral health support to address hoarding behavior. We are currently exploring the feasibility of an expanded program that would include behavioral health support whether through direct funding or in partnership with another agency in King County.

How can the federal government help your organization assist older adults and others with hoarding disorders?

More flexible funding is needed for us (as well as other non-profit and public-funded agencies) to tailor our services; for example, funding for ongoing behavioral health support to reduce hoarding behavior and declutter or clean out homes so that clients can receive other essential services such as caregiving, meal delivery, and transportation. More funding for qualified staff who can regularly outreach and assess clients who are isolated and more vulnerable so that they don't fall through the gaps in support systems. Expansion of Medicaid/Medicare funded services to include reimbursement for treatment of hoarding disorder.

Thank you,

Jams Stuivenga, LSWAIC, GMHS (they/them) | Clinical Supervisor

Sound Generations | 2208 Second Ave., Suite 100 | Seattle, WA 98121

Statement from Milene Maurin, Aging Care Management III, Westmoreland County Area Agency on Aging

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?
   Hoarding puts individuals at risk of losing their housing if they rent and those that own are at risk of having their property condemned and face fines and court costs that they cannot afford. We already have a housing crisis but it is even more difficult to secure housing for an individual with a history of hoarding. Hoarding is a repeat behavior without treatment and landlords know this.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?
   Our agency provides services in the home to help individuals age in place. The home health providers will not provide services to an older adult until the hoard is gone. Often with a hoard comes other safety issues like insects, rodents, waste and unhealthy animals. All of which are an additional expense to correct. A typical clean out of just basic living quarters can range from $6000.00 to $17,000.00. The additional cost of pest eradication can be in the thousands as well. Many people are unwilling to give up their animals thus adding to the inability to help with securing new housing.
   The community expects our programs, like Protective Services to go in and clean up the situation. However, the system says that if the individual has the capacity to make their own decisions then they can choose to live in hoarded conditions.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?
   We have become part of the Hoarding Alliance of Westmoreland County (HAWC). Also known as Fight the Blight. This is a small organization dedicated to helping people clean up their properties at a reduced rate or no cost at all depending on individual's resources. It has been a challenge for the organization to get funded and has primarily used fund raising efforts to expand. This limits the amount of people that can be helped. The other issue has been treating the mental health side of the Hoarding Disorder.

Westmoreland county does not have an expert in the treatment of hoarding. The group has leaned on the Philadelphia Hoarding Task Force to connect with training opportunities. The group has also partnered with local code enforcement, mental health programs, and community programs for support. Recently a support group has been established for those who collect and hoard and is part of the requirement to get assistance from HAWC.

4. <u>How can the federal government help your organization assist older adults and others with hoarding disorder?</u>
   Increase awareness of the root causes of hoarding through public education. Develop and fund programs designed to support an individual through every step of the process including mental health treatment. Enforce code violations for unsafe buildings, animal over population and unsanitary living conditions. Establish funding for more accessible, affordable, safe housing options for Older Adults.

Respectfully submitted,

Milene Maurin
Aging Care Management III
Westmoreland County Area Agency on Aging

Statement from Firefighter Adam Wood, San Francisco Fire Department (California)

Submitted March 25, 2024 through the International Association of Firefighters

Community Impact:
Hoarding Disorder has made many of our senior citizens prisoners in their own homes. Without access to care, or being accessible to caregivers, their medical conditions progress to acute levels. Numerous fire hazards accumulate in their homes.

Organizational Impact:
Transporting hoarding disorder victims with severe medical problems is extremely difficult, both for crews entering the home and those who carry the patient to the ambulance. Fires in these homes are difficult to locate and distinguish.

Response to HD:
We do not have a regular inspection program for private, single-family residences. Our first contact with a person suffering HD is usually in response to a medical or fire-related emergency.

Federal Assistance:
Programs that educate and support family members of seniors suffering from HD would certainly help.

Relevant Incident:
We responded to a fire in 2022 in the Bernal Heights neighborhood of San Francisco. The front entrance of the two-story house was completely blocked by accumulated furniture and debris. Rescue crews were forced to enter through the rear, downwind side of the house. All received burns during entry. The search for possible victims was conducted by crawling over three to five feet of debris piled throughout the house, leading to multiple cases of heat exhaustion. The elderly residents were safely evacuated.

Statement from Captain Robert Ford, Montgomery County Fire and Rescue Service (Maryland)

Submitted April 12, 2024 through the International Association of Firefighters

Community Impact: How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Over the last couple decades, I've seen a dramatic increase in hoarding which I believe has a lot to do with mental health and lack of mental health services. The hoarding directly impacts older people especially ones with less mobility, limiting access to parts of the house and making it extremely dangerous for the resident due to materials stacked on cooking appliances, blocked vents, blocked exits and trip and entanglement hazards.

Organizational Impact: How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

The increased hoarding epidemic has increased both fire and police calls and makes our jobs increasingly dangerous with the lack of easy access to the inside of the home. Fire loads and unsafe conditions which causes public safety personnel to be put in danger in properties that a lot of times need to be condemned.

Response to HD: How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What challenges, if any, has your organization faced while implementing that response?

The county has established a crisis reporting system. The system is designed to send out mental health professionals and counselors to try to assist the hoarding resident. Not sure exactly how it's working. I know of a couple of residence homes that were condemned, but are not condemned anymore and the situation continues at that residence. In my experience, most of the hoarding residents are old and do not have family members in the immediate area. Not only do we respond to medical and fire incidents with the hoarding residence many times we do welfare checks after receiving phone calls from their relatives who are unable to get in contact with them.

Federal Assistance: How can the federal government help your organization assist older adults and others with hoarding disorder?

Believe the biggest federal assistance that can be provided is for more funding for mental health support to the local jurisdictions.

Please feel free to share an incident where the response to hoarder house caused a health and safety risk to the firefighters or civilians on scene.

Several fire incidents at hoarder homes in which we were unable to enter the doors of the home due to hoarding conditions required us remove the hoarding materials to make entrance or extinguish the fire from the exterior of the home. I had one incident where firefighters unknowingly crawled through layers of human and pet feces that covered the floors. This required all the firefighters to go through extensive decontamination, medical exposure reporting and have their PPE condemned.

Statement from Firefighter Michael Wells, Prince George's County Fire/EMS Department (Maryland)

Submitted April 15, 2024 through the International Association of Firefighters

Community Impact: How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Unfortunately we have seen HD being the reason why populations such as older adults perish in fire within our department. Additionally, we see the squalor conditions impact patients in ems runs, i.e. patients living with mold, insect infestations and rats.

Organizational Impact: How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

I can think of multiple after-action reports that have listed HD as being a factor for defensive operations and maydays. Additionally, we are currently in a hiring crisis/mandatory overtime crisis. When HD calls are dispatched, usually additional resources are requested and we see the increase of service as well as the creation of service gaps by multiple units assigned to one call for manpower. This also has created a great deal of compassion fatigue for our members.

Response to HD: How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What challenges, if any, has your organization faced while implementing that response?

We have a premise hazard function within our 911 system. If a unit goes to a location for any type of hazard (hoarding, violent homeowner, etc.) a unit officer can make a note and it will be placed into the CAD. When units are dispatched to that address, there is a verbal "hazard warning" from the mobile data tablet (MDT) and the note of the hazard is within the CAD. Additionally, the dispatcher "should" give incoming units a heads up.

Our department also has a bariatric ambulance that can be dispatched on calls. There are some tools on there for hoarding scenarios such as hand trucks and nets to prevent collapses.

Federal Assistance: How can the federal government help your organization assist older adults and others with hoarding disorder?

Education to the public on hoarding conditions. Allow for social services to work with local fire departments to have an effective communication portal and consider assisting these residents with services. Enforce and fund fire code mechanisms to help identify these cases and stop them before they get out of hand.

Please feel free to share an incident where the response to hoarder house caused a health and safety risk to the firefighters or civilians on scene.

I had a friend get retired when we were dispatched to a house for a patient who was a priority 1 for sepsis. When they tried to go through the tunnel from a back bedroom, a large tub fell on top of his neck and he suffered disc problems that he could never recover from. To remove the patient and the crew from the house in a timely manner, my crew came with a tower ladder (bucket truck) and used chain saws to cut a bedroom window frame down to the floor and we removed the patient and crew by the bucket. I believe the house was condemned after that call.

Statement from Raymond A. Reynolds, Director of Fire & EMS/Police Officer, City of Nevada, Iowa

Submitted on March 21, 2024

1) HD has negatively impacted our community in 2022 and 2023 with home oxygen fires that caused two fatalities and burned two survivors with disfiguring injuries. The home were both hoarding homes and impeded the occupant's ability to exit the burning home. In both cases our department has been to these homes several times of medical calls, welfare checks, and calls for public assists. We see a significant number of falls in our aging population. In HD situations, those falls occur because they simply have no room to walk around without tripping.

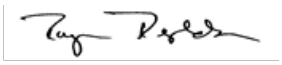
2) HD homes add a distinct hazard to firefighting. Firefighters will do anything to perform a rescue when the time comes. Hoarding homes present a larger fuel package, limit the ability to egress, and can easily trap firefighters in the home. To make matters worse, if a person in HD situation is part of the 750,000 home oxygen users who smoke on oxygen, there is a good chance the fire is accelerated by the oxygen rich environment. These are our growing concern in the fire service.

3) We have not been able to do much to address this issue since our time on scene with people is limited. We are a volunteer department so public outreach is limited. It is really hard to deal with as hoarding situations are not an easy 20 min solve.

4) I would like to see the government fund appropriate community risk reduction staff at fire departments. If we could get into our problem homes and establish a relationship with those people, we could work on resources for help. I think passing residential sprinkler provisions would help in a fire situation and pushing CMS to adopt a position similar to the VA to issue reimbursement for thermal fuses to be placed on home oxygen tubing. Mandating safety for home oxygen users who smoke should be simple since the fuses cost $4.45 and shut off the flow of oxygen when there is a fire.

Thank you for hearing me.

Raymond A. Reynolds, M.A., CPM, CCP



Director of Fire & EMS/Police Officer
City of Nevada
1209 6th Street
Nevada, Iowa 50201

Statement from Captain William J. Crews, Garland Fire Department (Texas)

Submitted April 15, 2024 through the International Association of Firefighters

Community Impact: How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Hoarding disorder has had a significant impact on older adults and those with disabilities in the City of Garland. The primary problem with HD in those groups is that the problem only worsens with time compounding the other problems that HD creates. The space within their home is finite and once the hoarded objects reach the walls, they begin to stack up. Quite often families, if any, have reached a point that they are unable or unwilling to help the affected person. The elderly or disabled are completely unable to reverse the situation even if they decide they want to.

The HD begins to create further mobility hazards for the person who most likely already has mobility issues. The trails through their residence become smaller and smaller making movement difficult. If there is a collapse of one of the piles the problem is worse.

The hoarding begins to create an unsanitary condition depending on what is being hoarded. If pets or vermin are present, which is often the case, pet/vermin fecal matter begins to collect in various places in the home. As mobility in the home begins to become a problem the hoarder begins to use the bathroom in various places in the home.

The longer the hoarding continues, the hoarder has a smaller and smaller area to reside and remain healthy.

Many of these people are in the situation as a result of mental health problems. The hoarding and resulting problems continue to erode that mental health and further worsen the problem.

Overall the person finds themself in a bad situation that worsens each day with no visible way out.

Organizational Impact: How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Responding to these homes often exposes our crews to unsanitary conditions that often should be considered a HAZMAT/Biohazard situation.

For our EMS crews, it creates many challenges especially if the person is completely immobile and they have to begin to determine how they will remove the person from the environment. Their attention also has to be diverted to their surroundings and those things that would threaten their health and safety.

We have also found that those that find themselves in these situations are reluctant to call EMS for help. As a result their health issues are much worse before EMS is called, making the call that much more difficult.

When the home is on fire, the difficulties are greatly amplified for responding crews. The primary difficulty being the increased fire load inside the structure.

Search of the residence for any trapped residents is nearly impossible. In many cases we have found a deceased resident in a hoarder home well after the fire is out and we have begun digging out the home. Quite often the resident is found buried in the hoarded items that collapsed as they tried to escape.

We have had a number of fires where firefighters became buried in collapsed piles of hoarded items.

For both EMS and Firefighting crews, response to these locations result in extensive decon of the responding crews. This results in extended time out of service.

Response to HD: How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What challenges, if any, has your organization faced while implementing that response?

The city of Garland has placed two Social Workers on staff. When HD homes are encountered, the responding crew can request assistance from the Social Worker. The Social Worker then works to connect the resident with resources, ultimately working to remove the resident from the resident into some type of assisted/full-time care.

The City, in conjunction with the Garland Fire Fighters Association, has assisted residents with cleaning out their homes. In these situations the Social Worker connects the resident with treatment with the hopes the hoarding will not return.

Federal Assistance: How can the federal government help your organization assist older adults and others with hoarding disorder?

Funds for local resources to use to assist these individuals would be one of the best resources that could be provided. Often, this is the roadblock to assisting these individuals.

A more difficult resource would be a streamlined and standard means to remove these individuals from these situations to protect them from themselves and to protect those that must respond to assist them.

Statement from Lieutenant Jeff Gauthier, Milwaukee Fire Department (Wisconsin)

Submitted April 15, 2024 through the International Association of Firefighters

Community Impact: How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Increased difficulty in access to patients and fire victims in instances where time is critical.

Organizational Impact: How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

Decontamination after runs is on the uprise due to high incidents of rodents, cockroaches and bedbugs.

Response to HD: How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What challenges, if any, has your organization faced while implementing that response?

Bed bug protocol and special decon vacuums and freezers to deal with infestation found largely in hoarder homes. Having to call for extra companies on fire runs to remove volumes of debris and "hoarding" situations. Slowing fire response in other parts of the city.

Federal Assistance: How can the federal government help your organization assist older adults and others with hoarding disorder?

Information campaign. Education. And assistance with removal.

Please feel free to share an incident where the response to hoarder house caused a health and safety risk to the firefighters or civilians on scene.

Multiple! Many fire fighters having to buy new station uniforms due to having to place clothes in freezers after bed bug runs or runs with rodent feces and urine.

Statement from Kathleen Frickanish, LPN

Submitted April 11, 2024

Please see below the answers to your questions about hoarding and how it can affect the seniors and the apartment buildings. These answers are based on 4 HUD senior living buildings in Lawrence County, PA.

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

Hoarding has put some of our residents in jeopardy of losing their housing because of lease violations.

- Hoarding can put other tenants at risk of pest's issues due to clutter and the unsanitary environment
- Hoarding can create fire safety issues
- Hoarding can cause resident falls and health issues
- 'Our managers and service coordinators make every effort possible to assist residents in obtaining services and connecting with agencies, providers, or caregivers but resources sometimes don't match the need

2. How has hoarding disorder impacted your organization, particular in its ability to carry out its mission?

- It can cause non compliance with our rules of safe, sanitary and decently maintained apartments
- Many times these individuals don't have any family support or the family gets frustrated and alienates from the individual – and all parties struggle to know where to turn for help (many don't know this is a mental illness) – we need to know who to call at what agency to be assessed and a list of options for treatment/placement/management
- They cause companies to be out of compliance with HUD real estate inspections

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

- Our organization does semi-annual apartment inspections which helps us discover any issues before they escalate. If there are issues a more progressive plan is initiated
- We also try to partner with any family supports or outside agencies with resident cooperation. The challenges we face are if the resident does not have any family or agency support, has financial barriers to getting help, or does not cooperate.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

- Advise housing companies of the resources available with a designated contact person to navigate services. Sometimes individuals may need to be placed in an assisted living setting. Humans service agencies in each county normally have housing that maybe certain cases could be transferred to if needed.
- Funding to assist residents with cleaning/decluttering/organization as well as mental health services that correlate to hoarding disorder would be helpful.

Thank you,

Kathleen Frickanish, LPN
Service Coordinator

Statement from Lee Shuer, Mutual Support Consulting, LLC

Lee Shuer, CPS **Mutual Support Consulting, LLC** **www.mutual-support.com**

April 15th, 2024

To the Senate Special Committee on Aging-

Unlike some mental health challenges, hoarding disorder (HD) is experienced not only by people afflicted, such as myself, but by the people and pets who live with us, near us, and emergency responders trying to help us in our times of greatest need. HD impacts an estimated 2 to 5% of the population, meaning roughly 350,000 residents of Massachusetts have such a strong attachment to our possessions that we hold on to them despite the risks of fire, falls, divorce, debt, and housing instability. It is the mission of myriad social service and emergency response agencies and departments to provide help before, during, and after a crisis related to their clutter. From Councils on Aging to fire departments to clinical and peer mental health professionals, the same question is raised at meetings across the commonwealth: "HD is everyone's problem, but whose job is it to help? And how?"

There are evidence-based interventions that are proven to help people with HD to acquire less and discard more, which ultimately leads to a safer living environment, but those strategies---primarily cognitive behavioral therapy and The Buried in Treasures Workshops---are not a quick fix. A problem that has often developed over the course of decades, in secrecy, can't be resolved overnight. In fact, even when people are in recovery or have overcome their urges to save, physical clutter remains.

There are many reasons why the clutter lingers, even after people have recovered emotionally. Though the symptoms of HD have been found to manifest as early as childhood, and most people are diagnosed by age 40. The age when the symptoms are most severe is 55+. By the time most people start to get better, they have become too weak, too overwhelmed, too embarrassed, or unable to afford the help they need to clean up. It's true that change starts from within, but it's the stuff above the surface that causes serious health and safety issues.

The education that professionals need to do their job in an efficient, effective, empathetic manner, must focus on harm reduction, trauma, and trust. Without evidence-based treatments that are rooted in these qualities, sustaining individual recovery is much less likely. Through programs such as smoke detector replacement, support groups at senior centers, community conversations that bring neighbors together to show solidarity and support, we can improve safety, bust stigma and extend a collective hand to those who need help, and empower and honor those who provide the help.

The corner stone of my business is partnering with organizations, municipalities, and individuals to find ways to overcome HD, from New England to New South Wales, Australia. When I'm working with residents who are in clutter crisis, my primary goal is to merge their unique needs and wants with those of the board of health; to have both comfort, and safety.

For example, I'm working with an 80-year-old in Western MA. They live alone in a 2000+ square foot home that they have owned for many years. When we started working together, over a year ago, the space was filled from wall to wall, from basement to attic, with heavy contents. What started as a job

to help clear pathways in her home quickly developed into a more intensive effort as we discovered that mice were living and wreaking havoc throughout. Now, instead of filling a few trash bags at a time to meet code, we need to hire a crew to pick up the ruined furniture, rugs, clothes, and various other possessions that have been rendered unhealthy by the infestation. As we make progress, the costs keep going up. Via funding through a local supportive housing organization, and the support of the board of health, police department, and senior services, we have made a great progress. In fact, as of this week, the first floor of her home is nearly decluttered! But what about upstairs?

Tomorrow we will continue to search for funding to continue the job which won't be done until the space is nearly empty so that the mice can be exterminated. When we started working together, I would ask when we could meet next, and her line was, "How about two weeks from never?" Sitting at her kitchen table last week she looked at me and said, "You know, your help has been the highlight of this past year for me." Those words brought tears to my eyes. Working with her has been one of the highlights of my year too. I'm grateful for the support I've had to fund our work but I'm worried that there won't be enough money to help get her to her goal, which is a safe comfortable home where her grandchildren are allowed to visit.

I'm impressed that our political leaders are pausing to ask how to be of assistance to those of us who help, have been helped, and want to help. It means the world.

Sincerely,

Lee Shuer, co-author of *The Buried in Treasures Workshop Facilitator's Guide*, with Dr. Randy O. Frost
International HD educator
Recovering Finder/Keeper

Statement from Karin Fried, Organizational Consulting Services

Submitted on March 29, 2024

Thank you for acknowledging the reality of Hoarding Disorder and the serious impact that it has on society! As a Professional Organizer and Advanced Hoarding Specialist (through ICD - Institute for Challenging Disorganization - www.challengingdisorganization.org) - I have been working with people with hoarding disorder for about 15 years. When I moved out to Montana (about 12 years ago) I had numerous clients with hoarding disorder and found that there were no resources available to help my clients (besides myself). There wasn't a single therapist that really understood hoarding disorder and therapists that worked with people with OCD (which hoarding disorder was classified under prior to it becoming a stand alone diagnosis in the DSM-5 in 2013) - refused to work with people that had hoarding issues.

Our national organization (ICD - Institute for Challenging Disorganization) - has worked tirelessly to help people understand chronic disorganization and hoarding issues. They have created numerous resources - such as the Clutter Hoarding Scale to help people understand the complexities of hoarding issues. They have worked tirelessly to provide education to Professional Organizers that work with people with hoarding disorder - a small and special group of Professional Organizers that help their clients to live a safer life with dignity.

As the only Professional Organizer and Advanced Hoarding Specialist in Montana, I have worked with numerous social service agencies and their clients to make their clients homes accessible and safe and also provide the support that the clients need and deserve - that they haven't gotten from their other providers. I have spoken to numerous agencies (fire department, health department, APS, aging services, numerous social service and mental health agencies and more...) and given seminars on the basics and the complexities of hoarding issues. These organizations had no understanding of hoarding issues and the emotional attachments that were involved. It was all about "the stuff". Clear it out and call it good! And there was no continuing support for their clients.

I put together the first Hoarding Conference in Montana in 2019 and it was well attended by numerous social service and city/county agencies. People wanted information.

I started the Missoula Hoarding Task Force to try and bring education and understanding on the complexities of hoarding to Montana. Most task forces are started and run by a social service or mental health agency - but no one stepped up to the plate - so Aging Services in Missoula wanted me to take the lead. We met in person and eventually (due to Covid) changed to Zoom meetings - which allowed more people throughout Montana to attend our meetings. Unfortunately, due to economic issues (social service and mental health agencies lost a lot of their funding) staff at these agencies were cut so attendance and participation at our meetings dropped significantly.

People want answers - people want help. My task force - like other hoarding task forces around the country - are information and support groups - they do not provide monetary assistance to clients. The social workers, mental health workers and city/county workers do not work for free. Yet, I seem to be expected to provide free education and services to my clients for free. As a business owner I cannot afford to work for free. But there is no one else in Montana to provide the education, resources or hands-on work that I do with my clients. A good proportion of

hoarding clients do not have the money to pay for any services that might help them live a safer life.

Our small group of Professional Organizers that work with hoarding clients (through ICD or NAPO - National Association of Productivity and Organizing Professionals) - are dedicated to making a difference in the world of hoarding disorder. We are working to be taken seriously. To have the medical profession understand that we are on the front line with our clients. To become part of the team that works with these clients - with therapists that give us the respect that we deserve for our understanding of the complexities of hoarding issues. Most therapists don't work hands-on with clients in their homes. They don't see the full scope of the problem.

If doctors would ask the "right questions" of their patients - hoarding issues could be dealt with a lot earlier in a person's life. If doctors could ask something like "can you use your stove", "do you have running water", "do you have a working shower", "are you able to walk around your home safely". But doctors are too busy to talk to their patients. And people - mostly seniors - get lost in the shuffle of bureaucracy.

Just about all of my hoarding clients are seniors. A good percentage have some sort of physical limitation (either age related or an illness that prevents them from doing a lot of the work). Most of my clients with hoarding issues also have other mental health issues - bipolar, ADHD, schizophrenia, autism spectrum, OCD, anxiety, depression..... A number of my clients have multiple mental health issues along with hoarding issues. It makes for a very complex dynamic.

To answer the questions in your inquiry:

1) Every social service or mental health agency in Missoula that I have spoken to or worked with - along with the fire department, health department, aging services - has shared with me that they see numerous cases of hoarding issues every month. Most are older adults, most have some sort of disability, some are veterans (who are reluctant to receive any help). These agencies have not been able to help these people - either because they don't have the education or resources (staff) - and no money to pay for any outside help for their clients. Because they are "adults" - they can "live anyway they want". Unless they are a danger to other people they will not remove them from their home (and severely hoarded condition). They feel useless to help these people.

2) Because most of the people with hoarding issues have limited (or non-existent) funds - there is nothing that anyone can do for them. Social service or mental health agencies don't work for free and can't hire outside agencies unless there is funding.

I started the Missoula Hoarding Task Force because I wanted to change the dynamics in Montana - to bring understanding and help to these people that are misunderstood. I pay for the website and all of the brochures that I created to give to these agencies. There is no "group" that funds the task force. I spend countless hours every week answering questions from agencies and families - without getting compensated for my work. Because I care.....

In the last couple of years - the social services and mental health agencies have lost so much staff (through lack of funding or a revolving door of social workers) - that they don't have the ability to allow their remaining staff to attend meetings or be more involved in the Hoarding Task Force. At this point - I am not sure how long I will be able to carry on alone.

3) The Missoula Hoarding Task Force (my organization) and my company (Organizational Consulting Services) provides a lot of education to various agencies and groups - on hoarding issues. I created a brochure that could be used by any and all medical & healthcare providers, as well as any and all agencies in Montana. The brochure provides basic information on hoarding issues that could also be used for families - so that there could be more understanding on how to help their family member with hoarding issues.

I also created a monthly survey - for various social service, mental health agencies, city/county agencies - to capture information on the exact number of hoarding cases that they saw each month. The purpose of this survey was to gather information - numbers - that would show the extent of hoarding in Missoula - in the hopes of eventually being able to apply for and get grants that could be used to help clients with hoarding issues. Unfortunately, even though everyone thought it was a good idea - only a couple of people actually returned these surveys. I ran the surveys for six (6) months - and received very little input. It was extremely disappointing - since I continue to get calls from these agencies about hoarding issues - so obviously it wasn't that hoarding just disappeared. The lack of response was disappointing and it also showed that hoarding was not a priority for anyone at these agencies or the city.

4) The federal government could help by providing funding specifically aimed at hoarding issues. Everything else seems to take priority over helping people with hoarding issues. More education for agencies (city/county....) about hoarding - and that it's a mental health issue that should be treated as such - and not just a "stuff" issue. Hoarding is a complex and widespread issue.

I have been running a 16-week workshop - "Buried in Treasures" (from Drs. Tolin, Frost and Steketee) for the last seven (7) years. I have clients from all over the world in my classes (London, Scotland, Australia, British Columbia, Mexico, Puerto Rico, Montreal, Toronto...and all over the USA). Hoarding is a very real and very serious issue - with little help available - which is why people are reaching out for any and all help.

I hope that the committee will learn a lot about the impact of hoarding issues from the responses that it will get from various sources. I know that various members of the Hoarding SIG (special interest group) through NAPO, that I am associated with, will be reaching out to share their thoughts. We are all very excited that someone out there is starting to take us seriously and we hope that there can be some forward movement in getting hoarding issues brought out from the darkness.

Thank you.....

Karin E. Fried, CPC, EMT-B, CTACC

Statement from Courtney Bearns

RFI on hoarding disorder
Response by Courtney Bearns, LSW, Ph.D.

1. How has hoarding disorder impacted your community, particularly older adults and people with disabilities?

I work with a small cat rescue based in Hudson County, NJ. We have on multiple occasions been called to assist with cases where an individual or family has been found to be hoarding animals.

This is an unfortunately common experience in our community, as it is a very high cost of living area and many residents – particularly the elderly and disabled – are struggling financially and unable to afford the high price of veterinary care. In our area, even using subsidized low-cost spay and neuter services (which also typically present major transportation barriers for residents in this high-density area where many people do not drive), the cost to spay or neuter a cat is nearly $100. This is financially unfeasible for many of our communities. A spay or neuter surgery at a local for-profit veterinarian is typically $300-500, which is even more out of reach. As a result, animals go un-fixed and are allowed to reproduce freely, which quickly leads to a dramatic increase in animals.

We often hear of situations where a well-meaning person takes in one or two animals, is unable or unwilling to have them spayed or neutered, and the animals end up procreating. Within the course of even one year, this often leads to horrifically inhumane and unsanitary conditions – residences in our area tend to be small apartments. The individuals become overwhelmed and are unable or unwilling to take action due to their psychological and logistical difficulties. What will typically happen in such a case is that the situation will escalate to the point that others – generally neighbors – will notice the health hazards, such as intense smells of animal urine and feces, and will call in the authorities, who alert the department of health.

My organization is called in to help with the immediate removal of the animals from the premises. However, similar assistance is not available for the individual or family members who were hoarding these animals. After the animals are removed, the core psychological factors leading to the hoarding symptoms are not sufficiently addressed, and they start collecting animals again. It is not unusual for us to be called to the same person or household multiple times across multiple years. Often we hear of this same pattern being repeated within families, so when we reach out to relatives for assistance, we find that the people we hoped would be social supports for the ill individual are themselves battling similar mental illness.

I am currently a licensed social worker, providing psychotherapy services to low-income residents of New Jersey, and my experience working with these hoarding cases is a primary factor that motivated me to pursue this career. It is utterly heartbreaking to be called in to assist with this type of situation and know how to help the animals, but to have minimal knowledge and nearly zero resources available to help the individual whose mental illness led to the situation in the first place. I returned to school to obtain a master's in social work because I wanted to learn more about how to help people in these kinds of situations.

2. How has hoarding disorder impacted your organization, particularly in its ability to carry out its mission?

My organization is a very small 501c3 organization that is completely volunteer-run. Our "staff" consists of three people, of whom I am one, and a loose network of volunteers who help by fostering cats in their homes and occasionally assisting with adoption events or other tasks. When we are called in to help with a hoarding case, it is a huge and immediate shock to our financial as well as logistical resources. We do not have enough space to immediately take in the numbers of animals in need of help, nor do we have the financial cushion to be able to provide the often-extensive veterinary care needed to save, rehabilitate, or humanely euthanize such a large number of animals all at once.

The animals taken from a hoarding situation are typically under-socialized, in poor health, and are frequently older than the typical easiest-to-adopt puppies and kittens people look for when seeking a new pet. These hoarding rescues tend to require more veterinary care, more time spent to help them adjust to living in a healthy and less-crowded home, and are typically seen as less desirable by adopters so tend to take longer to place in new homes. This creates an immense resource drain for our small, shoestring-budget organization.

This is just one of cases we have been called in for, but happened to get a lot of news coverage. I personally assisted with this case. https://www.cbsnews.com/newyork/news/west-new-york-animal-hoarding/

There are a number of additional cases that we have helped with "under the radar" by working with the ill individuals (and sometimes their neighbors or family members) to remove animals before the authorities became involved. One of the most difficult parts of this type of assistance

is motivating the person with the hoarding behaviors to allow us to remove some of their animals. As happens with hoarding disorder, they typically do not see their behavior as a problem, have intense emotional attachments to what they are hoarding (I suspect this is particularly the case with animal hoarding), and do not want to change or accept help. What is clear is that incarceration is not an effective solution to help those who are struggling with hoarding disorder, nor is it likely to create long-term change or improvement in symptoms. Instead, taking a punitive approach is likely to increase the individual's stress and may even lead to an increase in symptoms as the individual struggles to find other, healthier ways to cope with their emotions and psychological needs.

When we expend finances and resources to assist with these cases, it takes substantial resources away from our other goals and projects, such as reducing the homeless and feral cat populations in the area.

3. How has your organization responded to hoarding disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

Typically, our response has been, by necessity, one of immediate mobilization and networking after being apprised of a situation in need of intervention. Our organization has not currently been able to implement any specific initiatives to assist with hoarding disorder. We try to work closely with our community to provide education and non-judgmental support to encourage individuals impacted by animal hoarding to reach out for assistance before the situation becomes

unmanageable, but this is not always possible, particularly as individuals with hoarding disorder are often resistant to outside intervention. We would love to be able to provide mental health referrals, but as finances and transportation are such major barriers for afflicted individuals who may be in need of care, we currently have no mental health or social support resources we can provide. Language is another major barrier, as many of our community members are Spanish-speaking and have limited English proficiency.

4. How can the federal government help your organization assist older adults and others with hoarding disorder?

Government funding needs to be available to support both humans and animals in managing the symptoms of hoarding disorder. A single animal hoarding case can overwhelm the entirety of the resources available for animal welfare in some communities. Additional government funding to ensure the humane treatment of hoarded animals could make a tremendous difference in the community.

In addition, free in-home mental health and case management services for adults exhibiting symptoms of hoarding disorder could be monumentally impactful in stopping the cycle of hoarding behaviors and providing care for those in need. Case management and mental health counseling would be particularly helpful. As animal rescuers, we are often among the first to be called when someone suspects animal hoarding – as of now, in Hudson County, NJ, we have no resources to rely on to support the person in need. We can provide empathy and logistical support

for the animals, but we have no way to link the person with the type of care that would truly lead to recovery.

Case management services could help connect the individual with local supports, address the practical consequences of the hoarding behavior (such as services to help with cleaning and disinfecting), and to collaborate with housing authorities to address the problem in a restorative and non-punitive way.

Government funding to create specialized mental health services that are free and accessible to marginalized populations would be critical to raise awareness of symptoms and provide effective treatment.

Collaboration with national organizations that are already aware of the challenges with animal hoarding, such as Best Friends Animal Society, would be essential to ensure the animal welfare component of this disorder is managed appropriately. One example of this could be to increase funding for low-cost spay and neuter programs so that individuals who are well enough to recognize they need help are able to actually access veterinary care to help keep their pet population down to manageable levels.

Additionally, federal funds to support small-scale community groups, such as our own, and to establish community-based resources, such as social visitation services for socially-isolated seniors, would be important for establishing long-term change and support in these communities.

Statement from Eric Grainger, LMSW

Submitted on April 15, 2024

To Whom it May Concern,

1) Older people who struggle with hoarding in York County are being evicted from apartments and having their homes condemned at greater rates than people who don't hoard. They have greater rates of isolation and loneliness, therefore have more mental health problems. They experience more disabling medical conditions than people who don't hoard. Their homes are in need of more repairs from the clutter and people's deep shame that prevents them from utilizing plumbers, contractors and cleaning agencies. They are at greater risk for falls and hospitalizations.

2) As a police social worker, I have allotted more individual time, collaborative time and agency money towards this community problem than any other type of mental health disorder.

3) I previously developed and managed a hoarding program to help prevent evictions and condemnations, reduce risk of fires, health hazards and Adult Protective calls. We also utilized BSW, MSW, MOT students to assist with in-home organizing and mental health treatment. We helped organize support groups and facilitated Clutter Buddies matches where people helped each other reduce clutter and health hazards.

We established three Hoarding Task Forces in the state of Maine. We provided training to mental health providers, police, firefighters, first responders, colleges,

We needed to end the program after 10 years due to lack of funding.

4) We need federal grants specifically for programs focused on reducing the negative impacts of hoarding and accessing mental health and medical health treatment.

Sincerely,
Eric Grainger, LMSW

Statement from Ellen Denniger, Behavioral Health Specialist, Rogue Valley Council of Governments (Oregon)

Submitted on April 15, 2024

Hoarding disorder impacting my community:

I am a Behavioral Health Specialist providing treatment for people with hoarding disorder, both individually and in a group class for 4 months once a year. We use the Buried In Treasures book during the 16 week class to support people who acknowledge their difficulty with acquiring too many items, and difficulty with discarding items.

One case example is a 77-year-old woman living in a generational home that she inherited, including farm equipment, family photos and furniture. She was referred to me by a police officer when she could not comply with a weed abatement city ordinance and was verbalizing at City Hall that she will have to kill herself if she is cited with a daily fine. I met with her in her front yard because she had not let someone in her home for years due to hoarding and lack of cleanliness. She did not have hot water due to the hot water heater no longer working and she could not tolerate having a workman in her home to replace it. When rats dominated her home and yard, the neighbors complained, and the same police officer called me to collaborate once again to support her. A pest control company is donating their services to trap the rats and we have scheduled a date this month for the service to begin. The shame and grief around her hoarding behavior has impacted her physical health in terms of hygiene and unsafe living conditions. It has impacted her mental health because she is lonely and socially isolated, as she cannot have people over at her house to visit. A single woman in her 70’s is typically not able to keep up the yard and house independently. A lot of people do not have family or friends to help them, so they feel dismissed, invisible and not important in their own communities.

Other members of the class speak about the burden and responsibility they feel preserving family treasures and heirlooms when their own relatives, usually children and grandchildren, have no interest in inheriting these items. They feel compelled to find the right person or place to receive the items so that they continue to be valued. This older generation are very focused on not wasting items and finding someone who will buy them or use them. They understand that recycling essentially means it is likely the items

will end up in the trash and not being recycled. It is a hardship for older adults to load up large or heavy items to take to donation centers, as most places no longer provide pick up services.

The federal government can help by increasing funding for community programs that provide in-home caregiving to older adults and people with disabilities, fund programs that treat hoarding disorders with the class curriculum based on the Buried in Treasures book and fund genuine recycling programs that do the work that is intended. The government can pressure plastics companies to take responsibility for producing containers that are able to be recycled so that the cost is on them, not the consumer. In addition, funding programs that have trucks for pick up service to gather donations would be extremely helpful for older adults and people with disabilities that do not drive. Supporting older adults with funded programs in local senior centers to learn online banking and basic technology skills would help reduce the paper clutter that gathers in their homes because they are used to hard copy paperwork as a means of tracking finances and bills. Funding programs that support older adults and people with disabilities with completing basic housekeeping and yardwork is needed, as they no longer have the mobility to do the tasks themselves. Funding training for therapists and counselors to get CEU’s or a training certificate in treating hoarding disorder is needed, now that it is a mental health disorder in the DSM.

Statement from the University of Arizona College of Medicine Tucson, Center on Aging

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Senate Special Committee on Aging: Hoarding Disorder RFI Response

Hoarding Disorder (HD) is a challenging mental health condition and a growing public health concern. It is widely accepted that hoarding cases are underreported, and the population prevalence is likely greater than the national average of 5-6.2%. HD occurs in all cultures, income and education levels, and impacts both men and women. Before in-depth research of HD began in the 1990s, many believed that HD was somehow related to aging because most public cases involved older adults. However, we have since learned that onset usually occurs during adolescence, and hoarding behaviors are somewhat initially controlled by social cues from parents, roommates, and then spouses. Significant environmental impairment and related relationship complications usually begin during middle age, but treatment is rarely sought until the behaviors are hard to hide from outsiders, such as neighbors, maintenance workers, and landlords. Often, by the time outside agencies become involved, the person struggling with hoarding behaviors has aged into their fifties, and the situation has become both physically and environmentally hazardous to all occupants and close neighbors. As our older adult population continues to grow, we can expect more reports of HD. Further, there is a small sub-set of older adults who suffer late onset HD due to a traumatic event or loss. While this group will not have had a lifetime of acquiring and failing to discard items, they will need access to resources and direct services to ensure their health and safety.

Individuals living in a HD environment have a high risk for falls, infection, and respiratory problems. Some also struggle with co-occurring physical disabilities and mental illnesses such as depression, anxiety, and social phobias. Environmentally they (and their neighbors) have a high risk of pest infestations and fire, and often emergency medical and fire professionals have limited or blocked access to the dwelling and occupants.

It is important to note that without intervention hoarding situations will continue to deteriorate. The person struggling with hoarding behaviors will not wake up one day and say “I’m good now, I have enough stuff. I’ll stop acquiring items, and start discarding items I don’t need.” Intervention is needed.

1. How has Hoarding Disorder impacted your community, particularly older adults and people with disabilities?

Arizona Adult Protective Services (APS) confirmed 92 HD cases have been reported to their coordination team since August 2023. However, to accurately access HD impact on Arizona, standardized statewide case recording, management, and program evaluation for object, animal, and combined cases is needed. Further, client demographics need to be collected and shared to determine impact to specific groups.

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Example questions to ensure standardization include: 1) If a report doesn't meet APS case standards for services, but hoarding is evident, are those instances recorded to ensure accuracy of the state's HD prevalence estimate? 2) Does case management include counseling and behavior modification techniques? 3) When HD cases go beyond the care coordination team resources or available funding (i.e., client is unwilling to modify behavior; eviction occurs, and client becomes homeless or moves into a new dwelling; or services needed are not available in area) how are those cases recorded? 4) Are HD cases specific to object hoarding? Or are animal hoarding cases included? Are all HD cases, regardless of whether object and/or animal hoarding, managed the same? If not, how are they managed differently? 5) What is the average length of time required to resolve a HD case? 6) Is there a funding cap per case? What is the average amount of funding spent per HD case? If funding is received from outside sources to resolve (i.e., families, reduced direct service fees, or donations) are the funds and sources identified as separate from APS designated funding?

Note: In 2009, the San Francisco Hoarding Task Force conservatively estimated that local costs related to HD exceeded $6 million annually.[1] These costs are distributed across service providers, landlords, and individual families. In 2024, one can only assume annual HD related costs have at least doubled.

1. Mental Health Association of San Francisco. "Beyond Overwhelmed -The Impact of Compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care", (2009). https://www.mentalhealthsf.org/wp-content/uploads/2023/10/Task-Force-Report-FINAL.pdf

2. **How has Hoarding Disorder impacted your organization, particularly in its ability to carry out its mission?**

Since 2012, Dr. Lisa O'Neill (University of Arizona Center on Aging) has provided no cost local and national HD educational presentations to professional and community audiences.

Education is a critical intervention component for all professionals and direct service agencies that interact with HD individuals and environments. Basic education should include information on HD, communication tips, safety and health issues, assessment tools, treatment options, and available resources (local and national).

3. How has your organization responded to Hoarding Disorder, including through establishing any new or unique initiatives? What, if any, challenges has your organization faced while implementing that response?

In 2012, Dr. Lisa O'Neill partnered with Rae Vermeal (APS-Tucson) and Doug Clark (Assistant Attorney General-Tucson) to create the Southern Arizona Hoarding Task Force to educate professionals on HD, and expose members to all local direct service agencies who had anything to do with HD. The goal was for members to share what their agency did and didn't do for clients,

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as well as disclose fees per service. Our unfunded Task Force met monthly for three years to share information and de-identified case information for learning purposes. Our membership included over 100 members from 60+ agencies, including: University faculty, APS, CPS, medical and mental health providers, lawyers, police and fire departments, public health officials, housing departments, landlords, code enforcement, assisted living facilities, retirement community leaders, cleaning services, animal resources, and our region's Area Agency on Aging.

In 2015, it was decided our focus should shift to community members struggling with HD. Dr. Lisa O'Neill partnered with Jennifer Caragan from Pima Council on Aging (Area Agency on Aging) to start the HOPE workshop. This endeavor was also unfunded. We used our professional networks to disseminate flyers to community members via email and word of mouth. We stipulated workshop participants could only be individuals personally struggling with hoarding behaviors – family members and interested professionals were not allowed. We had 65 community members register for our first workshop. The overwhelming response to our first workshop was unexpected, but it clearly demonstrated people were looking for help. We restructured our weekly instruction to accommodate a large class as we were not interested in turning people away who were seeking help. The 10-week workshop was offered twice a year, with the 1.5-hour weekly classes held on Tuesday evenings. We ultimately averaged between 12-25 participants per workshop. Our last workshop ended in March 2020. Barriers to starting again include lack of funding, location issues, and our individual professional obligations.

4. How can the federal government help your organization assist older adults and others with Hoarding Disorder?

HD is a multi-faceted issue and requires a multi-disciplinary, coordinated response. Various task force models exist, each with their own mission. Popular missions include providing education for professionals and community members; connecting professionals so they may assist or resolve cases (not responsible for ongoing coordinated effort or case resolution); or providing direct coordinated services with a goal to resolve cases. These individual models are often un-or-underfunded, operate in isolation, offer fragmented education and/or services, and lack the ability to generate shared reports on case resolution, evaluation, and related costs/funding sources.

We believe a Statewide Task Force should include a blend of education and intervention missions. This model should be structured to ensure statewide case tracking, management, and evaluation with one State Lead agency partnering with designated agencies in each county. The State Lead and County partners need to have assigned paid personnel to manage cases and related workload. Further, Task Force membership should include all HD related agencies mentioned above in Q3. County partners should share de-identified lessons learned and evaluation reports bi-monthly, and the State Lead agency should share similar consolidated reports annually.

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The Federal government could offer training sessions to support States during their initial set-up phase. Provided expertise should include how to best determine the State Lead agency and designated County agencies, how to provide coordinated interventions, and ensure standardized statewide data collection and program evaluation. The Federal government could use the annual State reports to generate a national report and offer ongoing support via national educational conferences and networking opportunities so States can learn from other States. Additionally, funded research opportunities to further evidence-based HD prevention and management knowledge would be beneficial.

Thank you for the opportunity to provide our input. Please contact Dr. Lisa O'Neill with any questions [redacted]

Appendix C - Pennsylvania Data

The Pennsylvania Department of Aging provided Aging Committee Majority staff with data on confirmed cases of self-neglect due to hoarding disorder within Pennsylvania. The data cover three fiscal years and include statewide totals, as well as totals for each Area Agency on Aging. Note that the data may have been affected by the COVID-19 pandemic

Confirmed Cases of Self-Neglect Due to Hoarding Behavior

Unduplicated Count of Consumers with Hoarding Selected under Self-Neglect on PS Investigation Summary & Assessment (ISA), broken down by State Fiscal Year and Agency Data from 7/1/2020 to 10/13/2023, SAMS data as of 10/20/2023

	FY 20-21 (starting 2/1/21)	FY 21-22	FY 22-23	FY 23-24 Year-to-Date
AAA of Somerset County	1	0	0	0
AAA of Westmoreland County	3	6	8	1
Active Aging, Inc. (Crawford)	1	2	2	2
Adams County Office for Aging, Inc.	3	5	2	1
Aging Services, Inc. (Indiana)	1	0	3	0
Allegheny County DHS AAA	41	118	111	33
B/S/S/T AAA	1	4	7	1
Beaver County Office on Aging	0	7	9	3
Berks County Area Agency on Aging	13	12	6	4
Blair Senior Services, Inc.	5	7	12	8
Bucks County AAA	13	42	26	6
Butler County AAA	2	8	5	2
Cambria County AAA	3	9	3	1
Carbon County AAA	0	0	1	1
Centre County Office of Aging	2	4	4	1
Chester County Department of Aging Services	4	10	13	6
Clarion Area Agency on Aging	0	0	1	0
Clearfield County AAA, Inc	9	16	13	3
Columbia/Montour Aging Office, Inc.	5	18	16	2
Cumberland County Office on Aging	1	4	7	1
Dauphin County AAA	12	23	15	1
Delaware County AAA	2	10	11	4
Experience Inc. - AAA (Warren/Forest)	4	3	2	2
Franklin County AAA	0	1	1	2
Greater Erie Community Action Committee (GECAC	9	15	18	6
Huntingdon/Bedford/Fulton AAA	3	8	10	3
Jefferson County AAA	2	2	3	1
Lackawanna County Area Agency on Aging	10	19	26	11

	FY 20-21 (starting 2/1/21)	FY 21-22	FY 22-23	FY 23-24 Year-to-Date
Lancaster County Office of Aging	32	59	44	6
Lawrence County AAA	0	8	10	1
Lebanon County AAA	5	14	10	2
Lehigh County Aging & Adult Services	8	15	18	2
Luzerne/Wyoming Counties Bureau	3	0	5	0
Mercer County AAA, Inc.	1	3	0	1
Mifflin/Juniata AAA, Inc.	3	7	2	0
Monroe County AAA	6	18	9	2
Montgomery County Aging and Adult Services	5	16	26	7
Northampton County AAA	8	10	11	1
Northumberland County AAA	3	0	1	0
Office of Human Services, Inc. (Cameron/Elk/McKe	0	6	2	0
Perry County AAA	0	1	1	0
Philadelphia Corporation for Aging	31	50	108	48
Pike County AAA	1	8	4	1
Potter County AAA	0	0	2	0
Schuylkill County Office of Senior Svcs	3	14	9	1
Southwestern PA AAA, Inc. (Wash/Fay/Greene)	8	18	13	4
STEP Office of Aging	0	2	2	2
Union-Snyder Agency on Aging, Inc.	0	2	2	0
Venango County Older Adult Services	7	9	6	0
Wayne County AAA	0	2	0	0
York County AAA	6	11	14	2
No AAA	1	0	1	0
Total	279	618	630	184