

Allegheny County Hoarding Task Force
Needs Assessment Survey Results

Executive Summary

The mission statement of the Allegheny County Hoarding Task Force is to better understand the nature and extent of hoarding, increase education and awareness, and coordinate community resources in Allegheny County so community services are better able to respond to individuals with a hoarding disorder. To fulfill this mission, the Task Force realized that it needed to have a better understanding of the need for hoarding services and supports in the community. This was difficult because there is not currently a unified mechanism to track or follow incidents of hoarding across the county, however, the Task Force could develop a needs assessment survey to receive community feedback across a broad spectrum of professions and services so it could establish a broader understanding of the need. Hoarding is a complex disorder and requires a well-coordinated response across many service segments in our community. This needs assessment is a first step toward grasping the extent of hoarding in our community and understanding how community systems currently respond.

Who took our survey

The needs assessment survey was sent out electronically using Survey Monkey to stakeholder groups in the winter of 2017 and had 218 individual respondents. Survey-takers represented a diversity of professions and backgrounds, ranging from professional organizers to aging/elder care professionals, landlords, municipal employees and first responders. Thirty-one percent of respondents identified as aging/elder care service providers, 28% as non-profit organizations, and 23% as behavioral health professionals. Additionally, 11% identified as advocates for individuals with a hoarding disorder, 10% as a family member(s) and 7% reported being a neighbor of someone with a hoarding disorder.

Key Findings

The following are statistical highlights from the survey:

- 86% of respondents encountered individuals with a hoarding disorder at some point over the past year in their line of work.
- 68% of survey-takers tried to help individuals with a hoarding disorder attempt clean-up. Many survey-takers acknowledged a clean-up intervention alone is not enough to resolve the underlying hoarding disorder and requires therapy and on-going/other supports.
- Respondents identified the following factors in what they considered a successful intervention in a hoarding situation: Strong communication/rapport, affirming positive interactions and approach. They found these factors important to developing trust and positive outcomes.
- 51% of survey-takers identify family support and visitors as vital to improving the quality of life of individuals with a hoarding disorder.
- Of the 47 survey-takers that identified using landlord mediation interventions, 70% found this intervention to be successful in assisting individuals with a hoarding disorder improve their situation and avoid eviction.
- Of the 81 individuals identifying in-home supports as an intervention, 73% identified in-home supports as a successful intervention.

Summary Conclusions

Survey response options were both multiple choice and open-ended, providing a mix of quantitative and qualitative data. Five key conclusions recur throughout the survey and include:

- **A mixture of positive approach interventions is required to achieve successful outcomes in a hoarding situation.**
- There is a need to increase the number therapists/professionals trained to treat hoarding disorder.
- There is a need to provide on-going support services for individuals with a hoarding disorder, particularly in-home support.
- There is a need to increase the number of professional and community education and training activities related to hoarding disorder.
- Individuals with hoarding disorder do better when there is a support network of individuals with a hoarding disorder.

Background

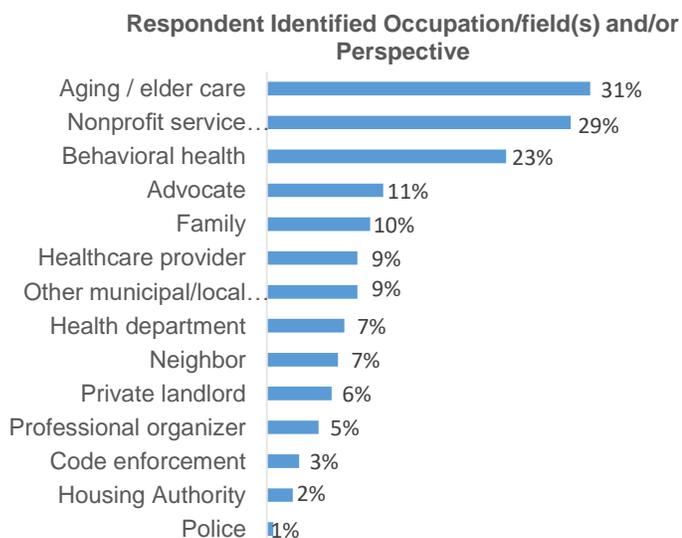
In 2016 the Allegheny County Hoarding Task Force developed a new mission statement. The mission is to better understand the nature and extent of hoarding, increase education and awareness, and coordinate community resources in Allegheny County so community services are better able to respond to individuals with hoarding disorder. To fulfill this mission statement, three workgroups were developed, which consist of an education workgroup, a resource guide workgroup and a needs assessment workgroup. The workgroups meet monthly, except for every third month, when the full Task Force meets.

The Hoarding Task Force is a community group, composed of members from various agencies and organizations working to address hoarding. The Task Force is purely voluntary and does not have a funding stream; however, it is staffed by the Allegheny County Department of Human Services (DHS). The Task Force does not intervene or consult on individual cases; instead, it works to address hoarding from a macro/system-level.

The Needs Assessment (NA) workgroup was tasked with defining the needs of individuals, families, communities and professionals regarding hoarding disorder. As a first step, the NA workgroup attempted to locate quantitative data related to hoarding across the county. However, it found that such data was limited in our community. Retrieving data that may currently be collected that is related to hoarding within our community is complex because of the multiple community segments that respond to hoarding related situations. Examples of a few community segments that respond to hoarding situations include: emergency first responders, behavioral health services, aging services, municipal and code enforcement, public health, animal control and protective services. Data that was identified is often siloed in a specific segment and is often de-identified making reliable summary conclusions difficult to ascertain. Given this situation, the NA committee decided to take a different approach and develop a survey as a first step to understanding the array of approaches the various segments are seeing related to hoarding.

The survey consisted of 13 multiple choice and eight open-ended questions that asked about experiences encountering hoarding. These included frequency and age, whether an intervention was attempted and if so, what interventions were successful or not successful and why. Respondents were also asked to identify their profession/survey-taker perspective, what resources are needed in Allegheny County and what would improve the quality of life for individuals with a hoarding disorder. The survey was developed through Survey Monkey and a survey access link was provided to Task Force members to forward out to their network group. As the survey was circulated by a web link and forwarding was allowed, there is no way to accurately determine the number of individuals who received the survey.

Who Took the Survey



Source: Hoarding survey, n = 162

To better understand survey-taker experience encountering hoarding situations and the interventions used by various community segments, respondents were asked to identify their field/occupation and/or perspective(s) informing their response. Many survey-takers selected multiple categories. The largest response categories were: aging/elder care (50), nonprofit service providers (47), and behavioral health (37). Additional frequently identified survey-taker perspective categories include: advocate, family member or neighbor, which indicates hoarding is encountered in both work and personal/private life.

As an example of multiple categories being selected, 12 respondents identified as being a “neighbor” of someone with a hoarding disorder and 10 of these respondents selected at least one other perspective from the top three largest response groups.

Encountering Individuals with A Hoarding Disorder, Including Age

The survey revealed 191 (86%) of the 218 survey-takers have encountered individuals with a hoarding disorder in their line of work. Only 19 survey-takers (9%) did not have an encounter through their line of work and nine (5%) were not sure. Of the 19 survey takers that did not encounter a hoarding situation, eight did not complete the survey.

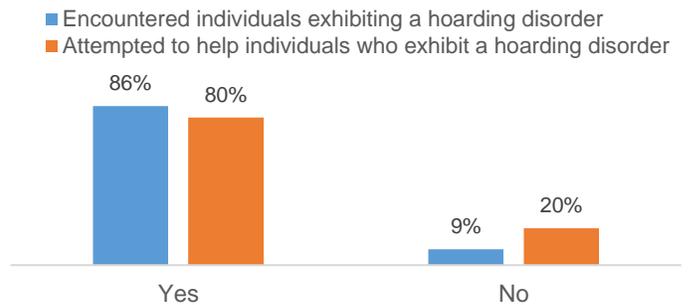
When asked about attempts to help individuals with a hoarding disorder, 171 (80%) report attempting to help and 42 survey-takers did not attempt to help. After reviewing which professions were unlikely to attempt an intervention, 25% (10) healthcare respondents report not attempting to help.

As estimated by survey-takers, over half (65%) of individuals with a hoarding disorder were 55 years of age or older. National data shows that hoarding is identified more commonly in older adults, however this is possibly because it is not apparent in younger populations. One study suggests hoarding behavior starts in teenage years and progresses through life.

Intervention Attempted and Need Identified

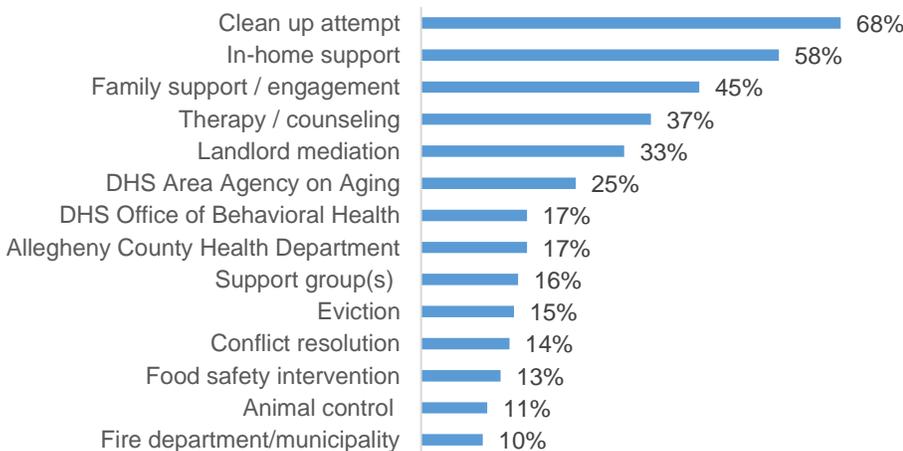
Survey-takers attempting to help individuals with a hoarding disorder were asked which interventions they used to help. Respondents could multi-select from a list of 14 possible categories. In two subsequent questions, the same 14 categories were used and survey-takers were asked to identify which intervention(s) were or were not successful and why. A total of 143 respondents identified at least one attempted intervention, with 137 identifying at least one success and 110 survey-takers identifying at least one unsuccessful intervention. Most individuals attempted more than one intervention.

Percent of Respondents Encountering and Helping Individuals With a Hoarding Disorder



Source: Hoarding survey
Encountered hoarding disorder, n = 218
Attempted help, n = 210

Interventions Used to Help Individuals with a Hoarding Disorder



Source: Hoarding survey, n = 140

Of the interventions attempted, a clean-up attempt was the most common, with 96 (68%) of 143 respondents attempting this approach. Clean-up was found to be successful by 41 individuals and 27 found it unsuccessful. Of those answering the original question, 28 did not respond to whether the intervention was successful or not. Best practice literature asserts that clean-up without other supports is likely to lead to trauma and hoarding will likely reoccur. Clean-up attempts were tried by 30 of 47 (63%) survey-takers from non-profit organizations, 29 of 50 (58%) individuals were from aging services, 22 of 37 (60%) survey takers identify as

behavioral health professionals. Additionally, 8 of 18 (44%) report being an advocate, 7 of 14 (50%) were healthcare workers, 3 of 11 (27%) identified as neighbors, and 2 of 10 (20%) were landlords. Non-profit organizations, behavioral health and aging staff are most likely to attempt a clean-up. While a smaller number of landlords, neighbors and healthcare workers attempted cleanup. 16 (53%) non-profit organization survey-takers identified success, followed by 13 (44%) from aging, one landlord, 4 (50%) advocates, and 2 (66%) healthcare workers. The respondent identifying a clean-up attempt as successful is generally consistent throughout professions.

There is a need to increase the number of therapists/professionals trained to treat hoarding disorder.

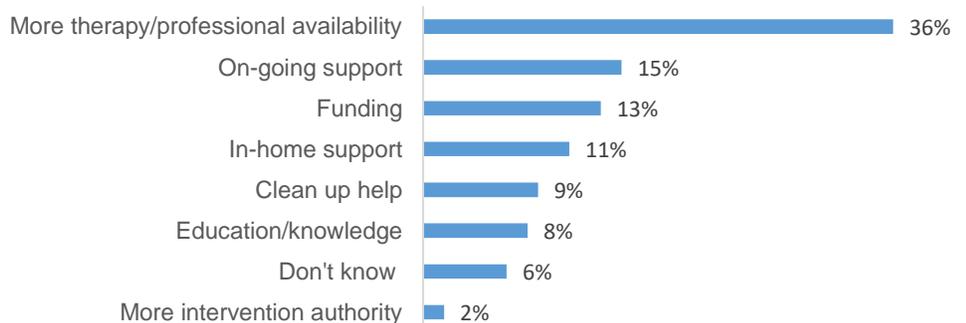
Therapy and counseling are identified by 53 individuals (37%) as being one intervention used to help individuals with a hoarding disorder. Therapy/counseling was identified as successful by 23 individuals and 18 individuals report no success. The survey shows most do not attempt therapy as an intervention but of those that do, 55% report success. Survey takers were also asked what supports are needed in Allegheny County to support individuals with a hoarding disorder. 147 (36%) survey-takers report the need for more therapy. Minimal therapy engagement may be associated with lack of available specialized hoarding therapy, access limitations (including transportation and cost), not knowing about therapy, and/or willingness of individuals to engage in therapy. The survey shows that 17 of 50 (34%) individuals from aging/elder care professions report referring individuals with a hoarding disorder to therapy, followed by 22 of 37 (60%) behavioral health professionals and 19 of 47 (40%) non-profit organization survey-takers. Conversely, 2 of 12 (16%) health department survey-takers, 2 of 11 (18%) neighbors, 7 of 16 (43%) family members, 1 of 10 (10%) of landlords, 4 of 14 (28%) from municipal government refer individuals with a hoarding disorder to therapy. Individuals reporting therapy success are evenly divided across professions, except that three healthcare professionals identify therapy as successful and only one reports therapy as not successful.

Survey responses indicate 65 (52%) of survey-takers report lack of hoarding disorder treatment professionals as a barrier to helping individuals with a hoarding disorder. 49 of 126 (38%) individuals identified the need for more therapy and professional availability in Allegheny County. Open-ended responses report limited availability of therapists specializing in hoarding disorder. Clients with a hoarding disorder and who are also engaged in therapy are often receiving therapy for co-occurring disorders such as depression, anxiety, obsessive-compulsive disorder (OCD) and not specifically for hoarding disorder.

There is a need to provide on-going support services for individuals with a hoarding disorder, particularly in-home support.

In-home support is a common intervention used by 81 survey-takers, with 49 survey-takers finding success and 18 reporting in-home supports not being a successful intervention. While the definition of in-home support was undefined in the survey, one possible definition includes in-home supports as a broad array of services to help with Activities of Daily Living (ADL) By identified profession, 81 survey-takers report using in-home supports, 32 survey-takers selected aging/elder care perspectives.

Support Needed in Allegheny County for Individuals with a Hoarding Disorder



Source: Hoarding survey, n = 126

“Regular home visits, professionals with the time to be in-home assisting person in understanding and overcoming the behavior, is very time oriented. Follow up must be regular and consistent”

-Quote from respondent

On-going support is another component that is identified as vital to helping individuals with a hoarding disorder. Of the responses, 19 of 126 (15%) individuals report the need for on-going support and 15 (11%) of individuals report the need for expanded in-home support.

“Having a specialist in the home allowed for folks to process their items in real time with compassionate trained individuals. Specialist are able to help clients cope with the stress of parting with their items and provide onsite organization skills particular to their needs”

-Quote from respondent

There is a need to increase the number of professional and community education and training activities related to hoarding disorder.

When asked what barriers professionals/front line staff encounter when attempting to help an individual(s) with hoarding disorder, 75 of 164 (46%) respondents report lack of training/knowledge about hoarding disorder as a barrier. When asked why certain interventions were successful, 20 of 74 (28%) of respondents identified communication/rapport as being a reason for intervention success. The survey reveals that 28 of 47 (60%) non-profit survey takers, 26 of 50 (52%) aging/elder care professionals and 21 of 37 (57%) behavioral health professionals report the importance of communication/rapport when helping an individual with a hoarding disorder. Other community segments identified communication and rapport as important to helping an individual with a hoarding disorder: 4 of 10 (40%) private landlords, 5 of 16 (31%) families, 2 of 11 (18%) neighbors, 6 of 14 (42%) healthcare providers. Behavioral health, aging and non-profit services providers are a bit more likely to identify rapport and communication as vital to engaging individuals with a hoarding disorder than neighbors, healthcare providers and families.

“I believe that some people respond when they know there are individuals who care enough to help them. Many do not know where to start or how to fix the problem. Having others engaged sometimes seems to help”

-Quote from respondent

Open-ended responses speak to the importance of empathy and trust when engaging an individual with a hoarding disorder. Survey-takers also identify trust as a vital component when helping individuals with a hoarding disorder. Education about approach is a component that may assist community segments engage individuals with a hoarding disorder.

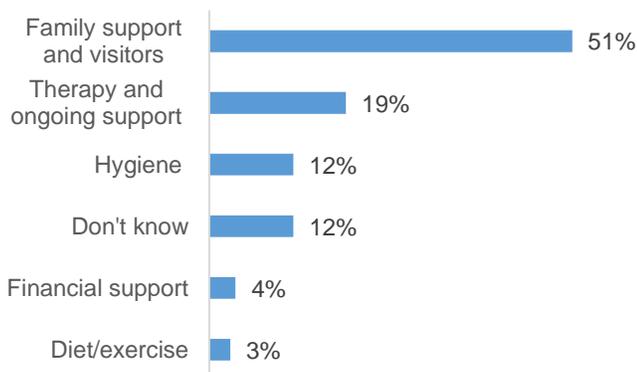
“Establishing trust with the person and then being present and assisting during the process of clean-up...”

-Quote from respondent

Of the 75 survey-takers identifying lack of training as a barrier when helping individuals with a hoarding disorder, 21 (28%) were behavioral health professionals, 13 (17%) identified from aging/elder care and 10 (13%) from non-profit organizations. Other community segments that identified education and training as a barrier include 8 (10%) individuals identifying as family members, 8 (10%) as advocates, 6 (8%) as healthcare workers and 9 (12%) respondents were from other professions. Behavioral health and aging/elder care providers are most likely to report the need for increased education and training related to hoarding disorder.

Individuals with hoarding disorder do better when there is a support network of other individuals with a hoarding disorder.

What Would Improve the Quality of Life for Individuals with a Hoarding Disorder



Source: Hoarding survey, n = 136

Survey-takers generally identify individuals with hoarding disorder as being socially isolated. More than half of respondents, 69 of 136 (51%), report that family support and visitors would improve the quality of life of individuals with a hoarding disorder. Respondents across all professions/perspectives report that increased support for individuals with hoarding disorder is important promote quality of life.

“Without the love and support that your family and friends can provide you, it’s easy to get lost in one’s habits.”

-Quote from respondent

Eight respondents to open-ended questions identify the benefits a support group to improving the overall quality of life for individuals with a hoarding disorder.